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UNIVERSITY OF ALBERTA

FAMILY PERCEPTION OF SUPPORT, SATISFACTION WITH CARE AND COPING
DURING TERMINAL STAGE CANCER

BY

FILOMENA NALEWAJEK

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE
OF MASTER OF NURSING

FACULTY OF NURSING

EDMONTON, ALBERTA

SPRING, 1992



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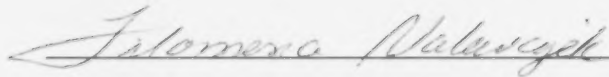
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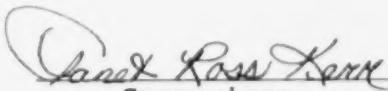
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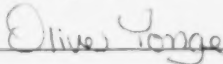
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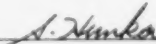
Janet Kerr


Supervisor

Olive Yonge



Steve Hunka



Date: November 20, 1991

DEDICATION

To my husband Ron whose love, encouragement and support gave me the inspiration and courage to achieve my goals. To my daughters Gina and Mara who never lost faith in their mother's ability to succeed. My success is theirs.

To my mother and father Rosa and Joe Pontieri who taught me that being a part of a loving family is one of life's greatest gifts.

To my sister Rena Methuen, and brother Tony Pontieri who were always there to help lessen my load.

ABSTRACT

The occurrence of a cancer illness affects the entire family. Families play a significant role during the time of illness in the support they give to the patient. Nurses are in an ideal position to offer support to those family members who are attempting to cope with stressors associated with illness. The hypothesis tested in this study was that perceived nursing support and satisfaction with nursing care are related to coping strategies that family members choose. A descriptive, correlational design was used to analyze the data. A sample of 49 family members of patients admitted to a cancer treatment facility with a palliative care prescription on their chart was obtained. Data was collected using the Family Crisis Oriented Personal Scales (FCOPES) (McCubbin, Olson & Larson, 1981), Family Perception of Supportive Nursing Actions (SNA) (Lewandowski & Jones, 1988) and Family Satisfaction With Nursing Care (FAMCARE) (Kristjanson, 1989) instruments. A biographical inventory was used to collect family demographic data. Reliability analysis revealed high internal consistency for the three measurement instruments. Factor analysis of the measurement instruments revealed five themes which described family coping on the FCOPES scale, four themes which described nursing support on the SNA scale and two themes which described satisfaction with care on the FAMCARE scale. Canonical correlation of subscales determined by the factor analysis, revealed a significant canonical correlation between supportive nursing communication with family coping strategies reframing and

seeking spiritual support. Findings from this study revealed that families used different types of coping strategies in dealing with their stress. Multiple regression analysis indicated a number of significant relationships among biographical family variables and subcategories of the three measurement instruments. Implications for nursing practice, education and research are discussed. Information generated from this study will assist in developing nursing knowledge and guide nursing practice in areas of family care.

ACKNOWLEDGEMENTS

I would like to express my sincere appreciation to all the individuals who have contributed to the successful completion of this study. First, I would like to extend my gratitude to the courageous families who gave their precious time to participate in this study. Without their genuine interest and cooperation this study would not have been possible.

I wish to thank Dr. Janet Kerr, my committee chairperson, for her unrelenting patience, encouragement and knowledge. The remaining members of my committee played a vital role in directing and facilitating the process of this study. I would like to extend many thanks to Dr. Steve Hunka who willingly shared his vast knowledge in statistical methods and analysis. I would also like to express thanks to Dr. Olive Yonge who was always encouraging.

I wish to thank the staff of the institution where data was obtained, especially Karin OLson, Janice Chobanuk and Tammy Hahn whose assistance made data gathering a possible and pleasurable task.

I would also like to thank Susan Shaw, for her assistance in using the SPSS/PC 4.0 program to analyze the data for this study.

I would like to express my sincere thanks to my employers at the Royal Alexandra Hospital who made it possible for me to take the time to complete this thesis and remain employed. I want to especially thank my peers in CERQA whose friendship support and never ending faith in my ability to succeed enabled my success.

Finally, I would like to express my gratitude to those

organizations which provided financial assistance for the completion of this study; the Alberta Association of Registered Nurses, the Alberta Foundation for Nursing Research, the Royal Alexandra Hospital Department of Nursing and the Edna Minton Endowment Fund. I wish to extend a special thanks to Mr. Minton who passed away during the course of this study, his genuine interest in this study was valued greatly.

TABLE OF CONTENTS

CHAPTER	PAGE
I.	INTRODUCTION AND STATEMENT OF THE PROBLEM.....1
	General Problem.....1
	Statement of Purpose.....3
	Definition of Terms.....4
	Theoretical Framework.....6
	Hypotheses.....10
II.	REVIEW OF RELATED LITERATURE.....11
	Introduction.....11
	Historical Overview.....12
	Research Development Regarding Dying Process..13
	Where Deaths Occur.....15
	Family Response to Illness.....16
	Needs of the Family.....17
	Family Coping.....21
	Supportive Nursing Measures.....23
	Summary.....27
III.	METHODS AND PROCEDURES.....29
	Design.....29
	Setting.....29
	The Sample.....29
	Referral Criteria and Target Population.....30
	Instruments.....34
	Procedures.....37
	Protection of Human Rights.....41

CHAPTER

PAGE

	Data Analysis.....	42
IV.	RESULTS, DISCUSSION AND INTERPRETATION.....	44
	Introduction.....	44
	Description of Participants in Study.....	44
	Family Member Variables.....	45
	Terminally Ill Family Member Variables.....	47
	Supportive Nursing Action Variable.....	51
	Family Satisfaction With Care Variable.....	54
	Family Coping Strategies Variable.....	56
	Hypotheses Testing.....	57
	Hypothesis Ones.....	57
	Hypothesis Two.....	59
	Hypothesis Three.....	60
	Family Coping, Support and Satisfaction.....	65
	Analysis of Other Variables.....	70
	Summary of Results.....	78
	Discussion.....	82
	Hypothesis One.....	83
	Hypothesis Two.....	85
	Hypothesis Three.....	86
	Discussion of Related Variables.....	88
	Discussion of Descriptive Findings.....	92
V.	CONCLUSIONS AND RECOMMENDATIONS.....	93
	Conclusions.....	93

CHAPTER**PAGE**

Limitations of the Study.....	96
Implications of the Study.....	96
Implications for Nursing.....	98
Recommendations for Study.....	100
Summary.....	101
REFERENCES.....	105
APPENDIX A.....	116
APPENDIX B.....	117
APPENDIX C.....	119
APPENDIX E.....	121
APPENDIX F.....	122
APPENDIX G.....	123
APPENDIX H.....	125
APPENDIX I.....	128
APPENDIX J.....	129
APPENDIX K.....	130

LIST OF TABLES

TABLE	DESCRIPTION	PAGE
1.1	Listing of Variables and Concepts.....	10
4.2	Summary of Family Demographic Variables.....	48
4.2	Patient Demographic Variables.....	50
4.3	Family Perception of Support.....	52
4.4	Responses to Questions on FAMCARE.....	55
4.5	FCOPES Subscale Range, Mean and Standard Deviation...	57
4.6	Multiple Regression Between SNA and FCOPES.....	58
4.7	Cronbach's Alpha Reliabilities for FCOPES.....	64
4.8	Themes and Corresponding Factors for SNA.....	64
4.9	Themes and Corresponding Factors for FAMCARE.....	64
4.10	Canonical Correlation for FCOPES, SNA and FAMCARE....	69
4.11	Analysis of Variance for SNA and Occupation.....	71
4.12	Analysis of Variance for FCOPES and Marital Status...	73
4.13	Analysis of Variance for FCOPES and Religious Practice.....	74

CHAPTER 1

INTRODUCTION AND STATEMENT OF PROBLEM

General Problem

Terminal illness is an event that disrupts the entire family. When a family member is admitted to hospital with a terminal illness such as cancer, the unexpected life event threatens the family's stability. Family members have reported countless stressors associated with this type of illness and use a number of coping mechanisms in an attempt to manage their stress. Coping with cancer is not a uniform process for families because the illness event is a unique experience for each family member, and each individual responds differently.

"The family constitutes the most important social context within which illness occurs and resolves" (Litman, 1974). The family as a basic unit in our society should also be recognized as a unit of health and if that health is threatened then it is a unit of treatment. "The sick member represents a subsystem within the whole system called family" (Roberts, 1986). As the illness increases in severity so do the stressors experienced by both the patient and the family. In fact if the illness is extremely critical the family tends to experience more emotional stressors than the patient. Common problems reported by families include disruption of usual routine, increased

fatigue associated with lack of sleep and inadequate nutrition, isolation from friends and other family members, role changes brought on by enforced independence and managing the family alone, and financial drain due to loss of an income (Bozett & Gibbons, 1983). The consequences for the family experiencing any number of these stressors can be devastating.

What people do in response to stressors in their lives has been described in the literature as coping. The family uses a variety of coping strategies to manage stress regardless of the effectiveness. Unfortunately, little is known about how families cope with terminal illness. Nurses have identified needs of families but not whether meeting those needs influences the family's ability to cope effectively. Nurses are in a position to influence the family's experience when a member is hospitalized. Through careful assessment nurses can tailor interventions to enhance the caregiving experience for the family. For nurses to provide better care for families, they first must understand family needs that enable members to cope. Is there a relationship between family need satisfaction and use of coping strategies? Could information regarding how families cope and the impact supportive nursing actions have on family coping serve to provide a basis for studies that test such interventions?

Statement of Purpose

The purpose of this study was to describe how family need satisfaction relates to family coping during the terminal illness of a family member. It is hypothesized that family members are able to use effective coping strategies when they receive support from nurses which they view as helpful. Awareness of what nursing support families need will no doubt enhance family nursing care. The research question used to guide this study was: What are the relationships between perceived nursing support, satisfaction with care and use of family coping strategies during a terminal cancer illness of a family member?

The specific research objectives were:

1. To describe coping strategies utilized by family of terminally ill patients;
2. To describe nursing actions these families find helpful.
3. To identify what areas of care families are most and least satisfied with when ill family members are hospitalized;
4. To examine the relationship between the family's perceptions of nursing support and use of coping strategies;
5. To examine the relationship between the family's satisfaction with care and use of coping strategies.

Definition of Terms

Family

Theoretical: Two or more individuals closely related by blood, marriage, or friendship. This includes cohabitating people of either sex, single parents and children, blended (step) families, and nuclear families. This term is used interchangeably with significant other.

Operational: Family members of patients receiving palliative care in a cancer centre who have consented to participate in this study.

Terminal Illness of a Family Member

Theoretical: Family members who have been diagnosed with an illness such as cancer, and have completed a course of curative interventions available to them. The disease has become irreversible and treatment for these individuals is often palliative.

Operational: Family members admitted to a cancer centre with a cancer diagnosis and for whom treatment aimed at a cure is no longer a reasonable alternative.

Palliative Care

Theoretical: A philosophy of care for individuals who are dying and for whom treatment aimed at cure

and prolongation of life is no longer appropriate. The focus of palliative care is control of symptoms and enhancement of quality of life, for patients and their family (Alberta Association of Registered Nurses, 1984).

Operational: Patients hospitalized in a cancer treatment centre with a palliative care prescription on their hospital chart.

Family Needs Satisfaction

Theoretical: Needs are internal tensions that result from alterations in some state of the individual. They are expressed in goal directed behaviour of the person which continues until goal satisfaction is achieved (Montagu, 1970). Needs satisfaction is the meeting of needs with the individual feeling a sense of adequacy and well being (Orlando, 1961).

Operational: Family members' responses to the Family Satisfaction with Care Inventory (Kristjanson, 1989) (see Appendix C for the FAMCARE Scale).

Supportive Nursing Actions

Theoretical: A verbal or nonverbal action employed by the nurse that is perceived as a buffering or intervening variable for stressful life events (Brandt & Weinert, 1981).

Operational: Family members' responses to the Supportive Nursing Action Inventory (SNAI) (Lewandowski & Jones, 1988) (see Appendix B for the SNAI).

Family Coping Strategies

Theoretical: Problem solving and behavioral strategies utilized by families in difficult or problematic situations (McCubbin & Thompson, 1991).

Operational: Family members' responses to Family Crisis Oriented Personal Evaluation Scales (F-COPES) (McCubbin, Olson & Larsen, 1981) (see Appendix D for the F-COPES).

Theoretical Framework

The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1991) was used to examine the relationships between perception of support, need satisfaction and family coping. In 1949 Hull was the first to examine family stress, by studying the effect war had on families. Since then researchers have attempted to find explanations for why families can experience similar stresses and react differently. Based on Hull's findings the ABCX Family Crisis Model was developed, explaining the relationship between an event, its' related hardship, the

effect this had on the family's definition of the crisis, and the family resources in handling the event. In the ABCX model the A represents the stressor, B are the existing resources, C is the family perception of the stressor, and X represents the resulting crisis. The model delineated the course of family adjustment which was marked by a period of disorganization, and time of recovery, followed by a level of reorganization.

McCubbin and Patterson (1983) identified four factors that appeared to influence family adaptation:

1. the pile up of additional stressors
2. family efforts to acquire new resources
3. redefinition of the crisis by the entire family
4. the role family coping strategies had on short and long term adaptation.

Following a longitudinal study of families who had a father or husband in the Vietnam war, McCubbin and Patterson found that adaptation results when families strive to achieve a new balance following the upset of a crisis. Positive adaptation is characterized by ongoing development of family members, unity of the family and maintenance of the family's sense of control and independence. Maladaptation is characterized by deterioration of family integrity, lack of personal family member development, and loss of independence.

The Resiliency Model evolved from the ABCX Family Crisis Model. McCubbin and McCubbin (1991) based the Resiliency Model of Family Stress, Adjustment, and Adaptation on the following assumptions of family life: that change and hardships are a natural occurrence in families; families have the capability to develop means to face changes and hardships; families develop strengths that enable them to adjust to stressors; families can be assisted to cope with their stressors by participating in helpful relationships and community resources, especially during periods of heightened family crisis.

Family crisis is a continuous variable that describes the amount of disruptiveness, disorganization, or incapacitation in the family social system (Burr, 1973). Family crisis has also been described as a transitional state in the family's effort to evolve and adapt to changes (McCubbin & Thompson, 1991). Therefore the family experiencing a family crisis is not characterized as having failed or in need of immediate intervention. The family's adaptive strengths, capabilities, resources, perceptions, support, etc. are the factors that determine how resilient the family is and whether the family will successfully adapt to changes precipitated by the crisis.

When a family crisis is precipitated by an illness, excessive stressors can occur. This means that multiple

changes create demands simultaneously. Hospitalization of a family member for a terminal illness can place a number of demands on the family, such as loss of an income, expenses incurred with hospitalization and visitations, loss of social contacts and fear of sudden death. For example a wife who quits her job to meet the demands of spending what little time is left with her sick husband while he is hospitalized, creates added financial burdens for the family. This, compounded by the emotional crisis of the impending loss of a loved one can be devastating for the family.

Any illness can precipitate a family crisis but a terminal illness requires that the family make major readjustments and alterations. Adaptive coping is the process of acquiring and allocating resources for meeting the demands as a result of the crisis. One way the family is influenced to cope is through external resources that have a supportive influence. Facilitating adaptive coping is a challenge for nurses working with families who are experiencing a terminal illness. Nurses can help the family cope by providing support to ease the strains of restructuring usual family patterns. The nurse's supportive role is enacted by careful observation and understanding of the family as unique individuals and as a system, which when intact is greater than the sum of its' parts.

Hypotheses

The hypotheses of the research are:

1. Perceived nursing support is related to the coping behaviours family choose when a family member has terminal stage cancer;
2. Satisfaction with nursing care is related to coping behaviours used by the family;
3. Family perception of support and satisfaction with care is related to the type of coping behaviours the family adopts.

Table 1, below, outlines the concepts and variables used in the hypotheses. As well, the instruments used to measure these variables and their authors are identified.

Table 1.1

Listing of Variables and Concepts by Instruments

Concept	Variable	Instrument	Author
Coping	Family Coping	F-Copes	McCubbin, Olson, & Larsen, (1981).
Satisfaction	Family Satisfaction	FAMCARE	Kristjanson, (1989).
Support	Nursing Support	Supportive Nursing Actions	Lewandowski, & Jones, (1988).

CHAPTER II

REVIEW OF RELATED LITERATURE

Introduction

In this chapter, a review of the literature related to the variables in the study as well as concerns in the area of family research will be presented. The topics that will be discussed include a brief overview of how studies related to the death and the dying process have evolved in the literature, the role of the family and their response to a terminal illness, family needs, family coping and nursing support.

The family, not only the patient, experiences the crisis, impact and consequences of a terminal illness. The purpose of this literature review is to analyze published research studies which look at the impact of a terminal illness on the family. Studies which identify supportive nursing behaviours, as perceived by family members of terminally ill patients, are reviewed as well. With the exception of a few exemplary papers, case studies and discussion papers that did not offer actual data are excluded. The current analysis of the literature does not represent all the relevant theoretical literature on family health and coping. Such a review would give a false impression of the amount and degree of knowledge available about the family experiencing terminal illness. The focus

of this review is limited to family experiences with terminal illness, acknowledging that research in this area needs to be challenged or examined before sound programs and services are developed to aid this population.

Historical Overview

Death, the final frontier in the journey of life, has been shrouded with mystery, fascination and fear since the beginning of time. In the eighteenth and early nineteenth centuries the preoccupation with death revolved around the many religious ideologies prevalent during that period, as well as frequent confrontations with death forced by inflated death rates. Historians, reviewing diaries from that era, discovered that people were frequently involved with caring for the dying. Death predominantly occurred in the home, enabling participation in rituals such as death watches, preparing bodies for burial, and officiating at funerals (Rosenblatt, 1981).

The rise of socialized medicine gave way to the organization of institutional care. This resulted in the old, invalid, and dying being cast out of the community and placed in separate institutions where they could be cared for by strangers. Shutting out the dying gave society the pseudo impression that death could be avoided or denied. Not only was death denied but it was a subject of taboo much

like acknowledgement of sex was for the Victorians (Gorer, 1965; Keck, 1977). Since death was only dealt with privately if at all, needs arising from the loss of loved ones were rarely met. The impact the loss had on surviving family members was therefore not considered.

With the sixties, society's interest in death was reawakened as tragedies from Hiroshima, Vietnam, Middle East wars, and acts of terrorism were confronted. Quality of life for the dying was raised as an issue of concern as death was acknowledged to be part of the life process (Pegg & Metze, 1981). Libraries became replete with texts and philosophical treatises about death, theoretical and personal responses to it, and, more recently, manuals and guides on "how to deal with it".

Research Development Regarding the Dying Process

During the past 20 years an outpouring of research on death and dying has sparked the attention of health care professionals. Researchers, from various disciplines, have added to the development of concepts such as death trajectories; death attitudes; biological, social, and psychological processes of dying; caregiving; and, bereavement and grief. Benoliel (1983), maintained that "human death and dying, as subjects for scientific investigation, are phenomena of the 20th century" (p. 102).

Research in nursing that dealt with the topic of death and dying, emerged during the sixties as well. Strongly influenced by sociological thinking, grounded theory approaches were used for developing theories on death and dying. Quint (1965), produced evidence that information control by nurses served as obstacles for women after mastectomy when dealing with an altered body image. Research studies revealed that terminal illness diagnoses had an influence on the nature of nurse-patient interactions (Hinton, 1967). Simmons and Given (1973) found that the majority of terminal patients welcomed the opportunity to talk about their concerns, giving rise to research that examined patterns of interaction between the patient and the nurse. There were indications that although nurses spent more time with dying patients, the quality of the interaction was strained and negatively influenced care the patient received (Vachon, Freedman, Formao, Rogers & Lyall, 1977; Wegmann, 1979). Lasagna (1970) asserted that the medical orientation to cure precipitated a half-hearted approach to the care of the terminally ill. This was supported by Kerr (1978) who stated that "death is often considered the ultimate failure of medicine to cure" (p.17). The urgency to enhance attention and care given to the dying is potentiated by the fact that death is one of the few life experiences common to all of mankind.

Where Deaths Occur

In the 19th century, three out of every 130 deaths occurred in hospitals, today the majority of deaths occur in institutions. Reasons for this shift have been attributed to the rise of modern medicine with the technology to prolong life, creating an illusion that the fate of death can be altered and perhaps even defeated (Cassell, 1975). Although 70% of Canadians die in hospital, some of the time during the dying process is spent in the home (Statistics Canada, 1983). There appears to be diversity in thought as to where death should occur. Krant maintained that, "institutions seldom allow for truly peaceful endings. The patient is forced into the role of combatant to the end." (1974, p.12). Rosenblatt (1981) after studying 130 diaries of individuals involved in home deaths reported that "even though there may be many economic and relationship advantages to home care for the dying, there may be for some survivors, a cost in terms of more prolonged or intense grief." (p.18). In support of this, Blakke & Pomietto (1986) asserted that, "it is the type of care provided, not the location of that provision that determines the results. The significance may not be between hospital and home but between the orientation of the health care team and the type of care offered." (p.72). There does appear to be consensus that regardless of where death occurs, the needs

of the terminally ill are influenced by the setting, and attention should be given to constraints of both.

Family Response to Terminal Illness

Significant others are affected by the demands and stresses imposed on them from having a loved one with a terminal illness. Giacquinta (1977), in researching the impact that living with cancer had on the family, concluded that terminal illness assaulted the integrity of the family system, since the entire family faces crisis when one member is dying. The significant other who is not prepared to deal with the physical, psychological and social consequences of having a loved one suffer from a terminal illness can develop many problems. Saunders (1967), found that family members who are not supported may separate themselves emotionally from the patient who is dying and suffer more mental and physical disturbances than the patient. At the same time Klein, Dean, and Bagdonoff (1967) studied 121 patients and their families and found that 67% of spouses had an increase in symptomatology during the illness. Spouses showed an increase in role tension resulting from heightened interpersonal conflict and frustration.

Stember (1977) studied the stress hospitalization had on family members. Several factors were identified that related to the stressful impact illness had on families: the

amount of stress experienced by a family during hospitalization of a family member was inversely proportional to the amount of hospital experience the family had and the chronicity of the condition; family stress was directly proportional to the severity of the illness, and the length of time the family had lived at their current residence. Therefore if a family member was experiencing a newly diagnosed terminal illness, the family was at greatest risk of experiencing acute stress.

Difficulties experienced by the family can adversely affect the patient's response to their illness (Howell, 1986). Patients are put in a vulnerable position when the family is having difficulty coping because the family is often the first line of support, nurturance and guidance for them (Lewis, 1986). If family members play such a crucial role in the well being of the patient, then meeting the needs of the family will benefit both the family and the patient.

Needs of the Family

Since a terminal illness affects the entire family and the stressful event of an impending death puts the family unit in a state of crisis, it becomes imperative that family needs are assessed (Cooper, 1984; Driever & Mc-Corkle, 1984; Gotay, 1984; Holing, 1983; Johnson & Norby, 1981).

Unfortunately, the family is often seen as the unit of support and refuge for the sick, and therefore not identified as the target of nursing care. The result is that members of the family become neglected, potentially interfering with the well-being of the entire family unit.

One of the first research studies on the needs of the family was done by Hampe (1975), who set out to describe the needs of spouses of terminally ill oncology patients. Twenty seven spouses of terminally ill patients were interviewed while the patient was in hospital and again after the patient had died. Hampe classified the data into the type of relationship the spouse had with the dying person, and the needs the spouses had identified for themselves. A shortcoming of the study was that Hampe did not identify whether the spouses needs were being met by the nursing staff. A similar research study was done by O'Brien (1983) however neither the stage of the disease nor the implications for nursing were identified. Both studies revealed that family members needed information about the patient's treatments and assurance that the patient was well cared for.

Dracup & Breu (1978) tested the effect of informing nurses about the needs of spouses in relation to grief and loss would have on whether the needs of the spouses were being met. One group of nurses were taught about the needs

of family in respect to the grieving process, the other group of nurses were not given any extra teaching. Spouses of the patients from both groups were interviewed as to how well their needs were met. The results indicated that the group of nurses who received the teaching had more needs met than the group that had not received the teaching. Since a number of uncontrolled, extraneous factors could have influenced the needs of the family, it was difficult to determine the degree to which the intervention was responsible for the results. The scope of the study was limited to knowledge of the nurse as the only factor examined in determining the needs of the family.

Greenley (1981), used a Q-Sort methodology to identify the needs of the terminally ill and their significant others in the home and in the hospital. Sixty needs were ranked by degree of importance as perceived by the respondents. The efforts of researchers such as Tringali (1986) and Kristjanson (1986; 1989a) gave rise to more comprehensive descriptions and a better understanding of family needs during a cancer illness. All three studies found that families ranked cognitive needs as most important with emotional and physical needs ranking second and third respectively. Another consistent finding was that families identified needs related to the well-being of the patient as taking priority to any of their own personal needs.

Several limitations of the studies were: small sample sizes; sampling techniques which excluded certain groups; and lack of clarity as to how needs were grouped into categories. Two out of the three studies had professionals identify the needs, then had families rank them. This method of identifying needs could be problematic in that without the family's input some important needs could be overlooked. All three studies focused on the needs of families and did not address nursing implications.

Hull (1989) completed a comprehensive literature review on family needs and supportive nursing behaviours. Several consistent findings arising from the review were that families identified their most important need as receiving information about their loved one; and, the second most important need as gaining assurance that their hospitalized family member was comfortable. Nursing interventions that family members found least supportive, and therefore were not perceived as needs by the family, were nursing behaviours that encouraged family members to open up and express their feelings. Inherent in the wealth of research findings that have identified the needs of family members of terminally ill patients, none report whether meeting those needs influences the families adjustment to the crisis and ability to cope.

Family Coping

Family coping is a multidimensional process. It is the way the family balances the effects of the stressors with available resources to promote adaptation (Bomar, 1989). There is agreement that the terminal phase of an illness poses the most challenge to family members' physical, social and psychological stability. Findings suggest that spouses experience a deterioration in their physical health, disturbed thought processes and a variety of emotional responses when confronted with impending death. The stress of the terminal illness period has been described as, far worse than the stress of widowhood, and severe enough to be linked to an increase in the morbidity rate of the bereaved (Parkes, Benjamin & Fitzgerald, 1969).

A number of research studies have focused on the impact of terminal illness on the family's ability to cope (Howell, 1986; Cassileth; Lusk; Strouse; Miller; Brown & Cross, 1985; Molter, 1979; Giacquinta, 1977; Vachon et al, 1977). Welch (1981) revealed, "there is some evidence to suggest that, in terms of psychological adjustment to illness, families may have more difficult problems coping than do patients" (p.366). Speedling (1980) spent six months as an observer in a nine bed intensive care unit. A significant discovery resulting from this study, was that family members appeared more fearful and anxious than did

patients, and were more pessimistic for the future.

Derdiarian (1989) identified two functions of coping operative in families experiencing stress. The first function, called instrumental, dealt with problem-solving efforts of the family and their use of environmental resources. The second function of coping, titled palliative, focused on how the family dealt with emotional distress. Vachon et al (1977) identified two sources that interfered with families' ability to cope: the location of care delivery and the level of communication between the patient and spouse. In contrast, spouses interviewed during the bereavement period reported that their ability to cope was mostly influenced by adequate relief of the patient's physically distressing symptoms, and the emotional support given to the patient and family (Parkes, 1978). A significant difference in family coping depending on the location of the ill family member was not found. A consistent finding in most of the studies was that categories such as: stage of the patients' illness; age of the family member; age of the patient, socioeconomic status; and ethnicity; are related to family coping (Lewis, 1986; Reider, 1989).

Supportive Nursing Measures

The research literature suggests that when families experience difficulties in coping with a terminal illness, they rely on supportive measures to help them cope (Gardner & Wheeler, 1987; Mayer, 1986; Oberst & James, 1985; Thorne, 1985). When a terminally ill patient is cared for in an institution, family members are in a position to observe, evaluate and participate in the care (Parkes, 1985; Wellisch, Jamison & Pasnau, 1977). The family can also be the recipient of care in the form of emotional support.

Several researchers have studied the concept of family as the object of care (Freihofer & Felton, 1976; Wright & Dyck, 1984). Perry & Smith stated, " the family as the basic unit of our society is also the unit of health and should, therefore, be the unit of treatment" (p.48). Since there is ample research which indicates that when a family member is terminally ill the family unit experiences stress, and that families cope with stress by receiving support from external resources, when nurses participate as one of the family's external resources they can then support the family.

There are many opinions of what constitutes supportive behaviours when caring for the family. Unfortunately most of what is identified as supportive has been done by health care professionals. Very few studies have focused on the

family's perceptions of supportive nursing behaviours. Freihofer & Felton (1976) used a Q-Sort methodology to identify the needs of bereaved individuals and the nursing behaviours that provided them with support. The most desired nursing behaviours as identified by the 25 subjects were: allowing the patients to do as much as possible for themselves; caring for the patient's hygiene needs; administering medication for pain as needed; and, ensuring the patient's physical comfort.

Welch (1981), completed a similar study using an instrument developed from previous research. Forty one family members were asked to look back on their experience and describe supportive nursing behaviours displayed by the staff at different stages of their loved ones illness. The findings from Welch's study were supported by other research findings which have indicated that families felt supported by the nurse when the patient was well cared for, and the nurses were available, honest and direct (Skorupka & Bohnet, 1982; Irwin & Meir, 1973). Mulhern (1986) divided supportive nursing measures into care or cure oriented. A retrospective chart analysis of nursing behaviours, directed towards terminally ill patients' family, revealed an increase over time in care oriented activities. These findings supported previous research indicating that families' need for supportive interventions increases as the

time of death gets closer (Dyck & Wright, 1985). Regrettably, the methods used in these studies did either not allow for input from family members or had family input after the fact. A limitation in research that asks individuals to recall experiences is that some valuable information may be forgotten or facts may appear less important over time. All three studies had small sample sizes and limited their population to family members of relatives who had been cared for at home.

In contrast, Lovejoy (1986) studied family members of terminally ill patients in acute care settings. Family members were asked to describe their experiences in the hospital and identify ways in which they received help from the nursing staff. The respondents were interviewed using open-ended questions and a 30 item questionnaire was administered. The findings indicated that family members responded to hospitalization with shock, uncertainty, accommodation, immersion or awareness. It was not clear how the researcher differentiated between responses to hospitalization and responses to the illness. The researcher identified three categories of behaviours which the respondents found helpful: validation of worth, provision of assurance, and preparation for the unknown. Unfortunately the measurement instrument was not discussed nor were statistics of reliability and validity provided.

Lewandowski & Jones (1988) developed an assessment tool that measured helpful nursing interventions, with members of cancer patients' families during three phases of cancer. The three phases were labelled as the initial phase when the cancer was diagnosed, the adaptation phase when the patient was receiving treatment and the terminal phase when treatment was stopped. The two most important nursing behaviours identified by the respondents were receiving clear explanations about the patient's care and treatments, and making the family member comfortable. Unfortunately the study was done by presenting vignettes that described situations involving a family member who had cancer. The respondents, randomly drawn from a telephone directory, had not necessarily experienced cancer or even serious illness in their family. The concern with the data derived from this study is that it does not represent the experiences of someone who is actually living with a crisis resulting from having cancer. Because the experience of having a family member diagnosed with cancer is unique, individuals may not be able to anticipate their needs nor identify the assistance they require.

Nurses are instrumental in supporting terminally ill patients and their families (Gotay, 1984). By virtue of their position and influence, nurses can impact on the quality of life and well-being of the family by intervening

in supportive ways. Nurses can prevent potential family maladjustment by being receptive to the unique needs of individuals. When nurses support the family the patient is indirectly supported. Having their needs met facilitates development of emotional strength enabling the family to support the needs of the patient more effectively.

Summary

Only in the last decade have nurses addressed the family as a conceptual entity. A substantial amount of research has been dedicated to studying the impact of a terminal illness on the family. Most of the researchers, though, have limited the definition of family to an immediate next-of-kin, have not clearly defined the nature of support and used exploratory or descriptive designs. Researchers have given equal attention to looking at the impact on family members caring for the terminally ill at home in a hospice setting or a hospital. Research to date supports that individuals who have terminally ill family members do have needs, which when met, enable them to cope with the crisis of the illness. Supportive behaviours directed towards the care of the patient and concern for the family have been identified as providing the most help. The nurse is in an ideal position to offer support to family members because the nurse has more contact with the patient

and the family than any other member of the health team.

The literature thus far has investigated many facets of family care. There is little doubt that a terminal illness in the family is a stressful event. There is a need for continued research in how families confronting a terminal illness can be assisted to effectively cope. Since what is known about the family is expanding, research should incorporate significant relationships as one aspect of the family. If the nurse expands the concept of patient to include the family then the family will become a part of the plan of care, transforming the role of the family from visitor to recipient of care. Nurse researchers have identified needs which family members of patients with cancer recognize as important. What has yet to be determined is whether or not meeting these needs influences how the family copes.

CHAPTER III

METHODS AND PROCEDURES

In this chapter the setting, population and research methodology will be described. Instruments used to collect the data will also be discussed.

Design

The concepts of need satisfaction and coping, as evidenced by the literature review, have been studied using experimental and non experimental designs. The purpose of this study was to contribute to nursing knowledge by exploring the relationships among perceived nursing support, satisfaction with care and coping in families who have a member experiencing a terminal cancer illness. Therefore, it was decided that the most appropriate methodology was a descriptive, correlational design.

Setting

The data for this study was collected in a large urban cancer facility in western Canada. The 76 bed facility has beds for both adults and children who are referred with a diagnosis of cancer. As well as having two inpatient units the institution provides services for 40,000 outpatients per year. The 24 year old institution holds true to its mandate of providing assessment, treatment and care throughout all

phases of the cancer illness. Boasting state of the art technology and promoting ongoing research done by a variety of health care disciplines, the cancer centre provides individualized care to the patient and the family.

The Sample

Referral Criteria and Target Population

The target population in this study was any family member of patients with a palliative care prescription on their chart. Since criteria had not been clearly established for identifying when a patient was terminally ill and the term held different meanings for different individuals, a prescription of palliative care provided the most reliable criteria for sample selection. A palliative care prescription for a patient was jointly decided by the physician and nursing staff when treatment aimed at a cure was not altering the progression of the disease and seemed no longer appropriate. The focus of palliative care was to ensure that the patient received treatments and medications that promoted comfort, relief of pain and quality of life. The patient and family were not always informed that the patient had been placed on palliative care unless the staff assessed that the information would benefit both the patient and the family. The majority of patients with a palliative care prescription died before they were ever discharged.

A nonprobability, convenience sample of all available participants meeting the requirements for selection was chosen from the entire population of family members of patients admitted to the cancer facility between January 1 and April 30, 1991. Since a random sample from the ideal target population could not be obtained, a representative sample of 49 participants from an accessible population was selected. In the selection process, inclusion criteria for the study were:

1. The participants were able to speak and understand the English language. This was necessary since the questionnaires were written in English.
2. The participants met the criteria of family members. Since a broad definition of family was used, it enabled individuals who were identified as significant to the patient to participate in the study.
3. The patient was receiving palliative care as specified by a palliative care prescription on her/his chart. The stage of illness was held constant in response to research findings which indicate that the amount of stress experienced by families is proportional to the severity of the condition (Stember, 1977).

4. The patient had been in hospital for a minimum of three days. Some hospital experience was necessary for the family to develop perceptions of what nursing actions were helpful, and assess their level of satisfaction with care given to the patient.
5. The patient had been diagnosed with cancer for at least three months. This criterion was included so that families who participated in the study had a minimum of three months to adjust to the fact that a significant individual in their lives had cancer. It was anticipated that families who had a three month period of adjustment would have a better idea of their needs and how they are coping with the crisis of a terminal illness.
6. The participants consented to participate in the study. A consent was required for ethical purposes as specified by the institution where data was collected.
7. The participants were 18 years of age or older. The questionnaires were designed to be used with an adult population.

Sample Size

A sample of 49 family members of patients with a palliative care prescription, admitted to a cancer facility in a large urban centre was chosen for this study. Determination of sample size was based on statistical concepts of power, effect size and significance criteria (Cohen, 1977). Statistical power is the probability that a particular test of statistical significance will lead to the rejection of the null hypothesis (Borg & Gall, 1983). A power of 0.60 should be maintained to increase the chances that a false null hypothesis is not accepted as true. Therefore in order to maintain a power of 0.60 and a medium effect size of 0.30, an alpha of 0.05 and a sample size of 49 was chosen for this study. With a sample size of 49, the null hypothesis will be correctly rejected 60 out of 100 times when $p=0.30$. A smaller effect size was not chosen as this would entail that a sample size greater than 150 would be needed. Given the scope of this research, obtaining a sample of that magnitude would be unrealistic in a reasonable period of time. A larger effect size is acknowledged as appropriate when anticipated research findings are supported by research previously conducted in the field (Cohen, 1977). The theory behind the constructs used in this study and the research reported in the literature suggests a relationship between family coping and

need satisfaction. Therefore a correlation among the measures of 0.30 should be closely examined.

Instruments

A biographical inventory questionnaire and three data collection instruments were administered to the participants of the study. The first instrument was used to measure family members' perceptions of supportive nursing actions. (see Appendix B). The Supportive Nursing Action (SNA) instrument includes 28 items which are measured on a 5-point Likert scale, where 1 indicates that the behaviour is most helpful, and 5 indicates that the behaviour is least helpful. Statements about nursing actions aimed at care the patient receives, such as "keep my family member clean", are interspersed with statements that assess how the family is treated, such as "shows interest in answering my questions". Participants were asked to include additional helpful nursing behaviours not included in the questionnaire.

The instrument was used to collect data on 150 subjects regarding nursing behaviours they would find helpful if a family member was diagnosed with cancer. The population sampled was chosen randomly from a telephone directory, given case studies describing individuals at various stages of a cancer illness and asked hypothetical questions about how they would respond if the individual in the case study

was a family member. Content validity of the instrument was established by a panel of experts who determined that the questions measured constructs of perceived support and need satisfaction of families experiencing a cancer illness. Measures of reliability were not reported (Lewandowski & Jones, 1988).

The second instrument, titled the Family Crisis Oriented Personal Scales (F-COPES), was used to measure family coping strategies (McCubbin, Olson & Larsen, 1981) (see Appendix C). The instrument identifies problem-solving and behavioral strategies families use when they encounter stressful situations. The F-Copes categorizes family coping strategies into five subscales: mobilizing families to acquire and accept formal support, such as from nursing staff; passive appraisal and acceptance; acquisition of informal support, such as from friends; reframing or redefining situations in a more positive manner; and seeking spiritual support. The instrument consists of 30 questions scored on a 5-point Likert scale, where 5 indicates that the behaviour is frequently used, and 1 indicates that the behaviour is not likely used. A total coping score can be obtained by adding up scores for the 30 items. Scores for each category can be obtained by summing up numbers for the group of questions representing each of the categories. Test-retest reliability (0.81), and internal reliability

(0.77) using Cronbach's Alpha, were reported on a study involving 116 subjects (McCubbin & Patterson, 1981). The process of tool development consisted of identification of coping strategies from coping literature, followed by compilation of a 49 item pilot instrument. Factor analysis of the 49 items revealed eight strong factors which then precipitated refinement of the tool to 30 items and five coping subscales (McCubbin, Larsen, & Olson, 1985). The F-COPES instrument has not been previously used with families experiencing a terminal stage cancer illness.

The FAMCARE Scale was adapted for use in this study to measure how satisfied the family was with nursing care received by the patient and family. (see Appendix D). Kristjanson (1989a,b) developed a 20 item Likert scale from a quantitative research study that identified indicators of family care satisfaction. A subsequent Q-sort study with 210 participants led to the reduction of items to the most salient indicators of satisfaction. A pilot study was conducted using the FAMCARE Scale with 40 family members of advanced cancer patients. The reported reliability with test-retest correlations was 0.91, and internal consistency estimates of 0.93. Criterion validity was reported as 0.80 and 0.77 with the McCusker Satisfaction Scale.

In addition to the three instruments, a biographical inventory was administered to the participants of the study.

A number of items such as age, gender, nationality and experience with past hospitalizations, made up part of the questionnaire. Items included in the biographical inventory were based on factors which were reported in the literature to have an influence on family satisfaction and coping.

Procedures

The initial step of ethical approval from the Faculty of Nursing and the hospital where data was collected, was obtained over a 6 month period from June, 1990 to December, 1990. Delays in obtaining ethical approval included concerns with use of the term palliative. It was recommended that the researcher use the descriptor, 'a patient with cancer for whom treatment aimed at a cure is no longer a reasonable alternative', to replace the term palliative in the study. The study was explained to nursing staff on both inpatient units in the cancer facility. Presentations describing the purpose, significance and procedure of the study were delivered to staff on days, evening, and night shifts. A poster outlining the particulars of the study was also posted in the charting area of both units. The researcher attended staff meetings to inform staff who had not been able to attend the presentations and answer questions about the study.

The investigator reviewed the patient Kardex on both

inpatient units regularly to identify patients whose family members might meet the criteria for inclusion in the study. The investigator determined that the patient was receiving palliative care by ensuring that there was a palliative care prescription on the patients Kardex. A list of potential participants was formulated and discussed with the respective head nurse on each unit. From the list of potential participants, patients who had family who visited and were not imminently close to death were chosen. Families of patients close to death were in need of privacy and time to be with their loved ones therefore asking them to participate in the study was determined to be inappropriate. Occasionally, a family who met the criteria was excluded from the study based on the assessment and request of the head nurse. Rationale given for excluding the family was that family members were either extremely upset, experiencing many conflicts, or assessed as having difficulty adjusting to the illness.

The investigator then located family members of patients meeting the criteria. The families were approached while they were visiting with the patient and asked to speak with the investigator in a private location. Only one member from each family was approached about the study. According to Gillis (1983), when the family is treated as context to a research question, the collection of data may

be validly undertaken with an individual client referent. In this particular study the participant's perception of the family was sought. The investigator explained the study briefly and handed the family member an information letter containing a more detailed description of the study, investigator's name and contact number if the participant had questions. Family members were instructed to indicate their wish to learn more about the study by placing an X beside the statement that indicated they would like to be contacted by the researcher and where they could be reached. If they were not interested in the study they were asked to place an X next to the statement that indicated they did not want to be contacted. Upon completion of the form, family members sealed their response in an envelope addressed to the investigator and submitted it to someone at the front desk who in turn placed it in a larger envelope with the researchers name and title of study. The researcher retrieved the envelopes every 2-3 days and contacted individuals who expressed interest in learning more about the study.

Arrangements were made with family members to meet with the investigator who would explain the study. All the participants wanted to meet with the researcher while they were visiting the patient in the hospital. The investigator explained the study in greater detail and a consent to

participate form was completed. All family members who had gone as far as having the study explained the second time agreed to participate. Some of the participants expressed interest in participating with the study when approached initially and therefore the researcher proceeded with the detailed explanation of the study and the consent form immediately.

All family members were given the questionnaires in a large envelope, asked to complete it alone, while in the hospital and return it to the investigator. The investigator was available for the family during this time but was not approached with questions or comments while the family filled out the questionnaires. The majority of participants completed the questionnaires within 30 minutes and immediately returned them in a sealed envelope to the investigator. Several comments expressed by family members when submitting their envelopes included: "there is a need for more studies like this", "it's about time nurses were interested in what the family thought", "families appreciate being recognized as having needs".

Protection of Human Rights

This study was approved by the University of Alberta Faculty of Nursing Ethics Committee and the appropriate review committees at both the nursing and medical board

levels of the hospital where data was collected. Signed informed consents were obtained from the participants following explanation of the study. The informed consent included a brief overview of the study, the extent of involvement by the participant, risks and benefits, assurance of confidentiality, the right to withdraw from the study at any time, the opportunity to ask questions, and the name and phone number of the primary investigator and thesis advisor. Participation in this study was completely voluntary. Confidentiality was assured by conducting the questionnaire completion in a private area of the hospital and submitting responses to the investigator in a sealed envelope. Individuals who were interested in the study, as well as those who were not interested, submitted their responses in a sealed envelope to the nursing desk. This procedure ensured that the nursing staff could not identify who was participating in the study. A coding system was used so that individuals were not personally identified on any of the instruments. A patient advocate from within the hospital was assigned to the study to deal with any issues of concern or dissatisfaction expressed by the family. An occasion did not arise where assistance from the patient advocate was warranted.

Data Analysis

Data generated from the Supportive Nursing Action, Satisfaction With Care, Family Crisis Oriented Personal Evaluation Scales, and Biographical Inventory instruments was entered into a personal computer and analyzed using SPSS/PC 4.0 software program. Variables were reported and analyzed using descriptive and correlational statistics. Statistics of central tendency and frequency distributions were used to summarize the biographical and instrument related variables. Major variables were analyzed using a Pearson product moment correlation statistic.

Factor analysis of both the SNA and FAMCARE instruments was done to determine variables with a common factor. The factors were then analyzed for emerging themes or concepts. The factor analysis generates a correlation coefficient for each of the variables in the questionnaire, which identifies how the variable loads on a particular factor. Only variables which loaded higher than 0.40, on a factor having an eigenvalue greater than one were used in the analysis.

Determination of reliability was done on each of the instruments, as well as for each of the subscales identified through the factor analysis. Cronbach's Alpha was used to determine internal consistency in the answers to questions.

The Pearson product moment correlation was used to determine the strength of association between family

perception of nursing support, family satisfaction with care and family coping. The Pearson product-moment correlation was also used to determine the strength of association between F-COPES subscales (acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, and passive appraisal), SNA subscales (communication, comfort measures, empathy, respect of privacy), and FAMCARE subscales (communication of information, meeting physical and emotional needs). Analysis of variance (ANOVA) procedures and t-tests were used to assess the mean difference for variables of family coping, satisfaction with care, perception of nursing support, and groups derived from the Biographical Inventory instrument.

CHAPTER IV

RESULTS, DISCUSSION AND INTERPRETATION

Introduction

The purpose of this study was to describe how family perception of nursing support and need satisfaction relate to family coping during the terminal phase of a cancer illness. The hypothesis tested in this study was: there is a relationship between family perception of nursing support, family need satisfaction and family coping strategies.

Data analyzed in this study was collected over a four month period, from a convenience sample of family members of patients receiving palliative care in an urban cancer institute in western Canada. Data was entered on an personal computer and analyzed using the Statistical Package for Social Science (SPSS/PC 4.0). Descriptive statistics were used to summarize characteristics of the participants in the study. Other variables in the study and the hypothesis were tested by using Pearson product moment correlation coefficients, analysis of variance and t-tests.

Description of Participants in Study

Forty nine family members of patients admitted with a terminal cancer diagnoses participated in this study. Only two family members that were approached declined to participate. Reasons given for not participating were not

enough time to spend on filling out questionnaires and a desire not to discuss family matters. The participants were all over 18 years of age, able to speak and understand the English language and met the criteria of being a family member. Participants were family members of patients admitted to one of two units of a cancer treatment centre who had a diagnosis of cancer and a prescription of palliative care on their charts. All the patients were 18 years of age or older and had been hospitalized for a minimum of 3 days. The demographic family member characteristics examined in the study were: age, sex, relationship to patient, ethnic background, marital status, religious practices and occupation. Ill family member variables examined were: reason for admission, length of illness, and previous hospitalizations. If a participant neglected to provide an answer to a question a "missing" value was attached to the response when data was entered to ensure accurate analysis of the data. In cases where the same question was left blank on repeated questionnaires an attempt is made at explaining plausible causes. A description of the demographic variables follows.

Family Members

Thirty three (67.3%) females and 16 (32.7%) males participated in the study. The mean age was 42.9 years

($SD = 13.8$). The oldest family member was 73 years old and the youngest was 19 years old. Family members were asked to describe their relationship to the patient. Seventeen (34.7%) family members described themselves as daughters, fifteen (30.6%) as spouses, seven (14.3%) as sons, and the remaining 10 (20.4%) as siblings, parents, partners, or grandchildren. Thirty six (73.5%) of the participants were married and the remainder were either divorced, single, separated or in a common law relationship. Family members were asked to state their ethnic background. Twenty six (53.1%) reported that they were Canadians, nine (18.4%) stated they were European and the remainder were either British, Asian, or Middle Eastern. In response to questions relating to family religious practice, of the 38 (77.6%) that admitted to having a religious belief, twenty (40.8%) were Protestants, fourteen (28.6%) were Roman Catholics, and four (4%) practised various other forms of religion.

Twenty seven (55.1%) of the participants in the study were employed. The remainder were either unemployed, retired or homemakers. Family members occupations included 11 (22.4%) white collar workers, four of whom were employed in the health field, 11 (22.4%) blue collar workers, five (10.2%) reported being self employed, three were students, and one was a farmer. The distinction between working classes was made for the purpose of categorizing both type

of employment and education. Individuals who had attended a formal university or college and earned a profession were classified as white collar. Examples of white collar workers included teachers, engineers, nurses, lab technicians, journalists, etc. Classification of a participant as a blue collar worker included occupations learned either formally through a special school or informally through practice. Some examples of blue collar workers include trades people, hairdressers, and store clerks. Summary tables of each of the biographical family member variables are presented in Table 4.1

Terminally Ill Family Member Variables

Severity of illness was determined by a prescription of palliative care on the patients chart. The prescription was determined by the patient's physician in consultation with nurses on the unit and, when appropriate, the family. A prescription of palliative care was given to patients who had undergone aggressive treatment for their cancer and all clinical indicators suggested the disease was progressing beyond hope of remission or cure. The interpretation of palliative care was that treatment aimed at cure ceased and that treatment focused on maintenance of daily activities with minimal amount of pain or discomfort.

Table 4.1

Summary of Family Member Demographic Variables

	Mean	Range	Std Dev
Age	43	19-73	13.81

VARIABLE	FREQUENCY	PERCENT
Sex		
Female	33	67.3
Male	16	32.7
Relationship to Patient		
Partner/Spouse	16	32.6
daughter	17	34.7
son	7	14.3
sibling	4	8.2
parent	2	4.1
grandchild	3	6.1
Marital Status		
Married or Commonlaw	37	75.5
Divorced or Separated	5	10.2
Single	7	14.3
Religious Practice		
Catholic	14	28.6
Protestant	20	40.8
Other	4	8.2
None	11	22.4
Ethnic Background		
Canadian	26	53.1
European	9	18.4
British	6	12.2
Other(Asian, Middle Eastern)	6	12.2
Employment		
Employed	27	55.1
Homemaker	8	16.3
Unemployed	7	14.3
Retired	7	14.3
Occupation		
Professional/White Collar	7	14.3
Health Professional	4	8.2
Blue Collar	11	22.4
Self-employed	6	12.2
Student	3	6.1

Patients admitted to the cancer treatment centre where data was collected for this study, went to one of two inpatient units. Both units were similar in their physical layout, number of patients and severity of patient illness. Both units operated under the team nursing concept and had similar leadership structure. Seventeen (34.7%) of the patients whose family participated in the study were from unit A, and thirty two (65.3%) were admitted to unit B. Both units were examined for potential participants, but Unit B had a greater population of terminally ill patients during the four month period in which data was collected.

Forty nine family members of patients admitted to Unit A and Unit B between December 1990 and March 1991 participated in the study. Twenty nine (59.2%) patients had been diagnosed with cancer for longer than a year. The remainder were equally split, ten (20.4%) of whom had known about their cancer for six to twelve months, and ten (20.4%) who had been diagnosed for only three to five months. Forty (81.6%) patients had been hospitalized previously for treatment of their cancer, with twenty seven (55.1%) having been hospitalized at least once and at maximum five times. Ten patients had been hospitalized six to ten times and three had been hospitalized more than ten times.

The predominant reason given by the family for patient admission to hospital was cancer ($n = 20$, 40.8%). A

possibility exists that this particular group of participants were unsure as to why the patient was admitted and assumed that it had something to do with the family member's cancer. Other reasons given for hospitalization included symptom control ($\underline{n} = 15, 30.6\%$), pain control ($\underline{n} = 6, 12.2\%$), treatment ($\underline{n} = 6, 12.2\%$) and cure ($\underline{n} = 1, 2.0\%$). Patient charts revealed that all patients whose family participated in the study were admitted for control of pain and/or adverse symptoms associated with progression of the cancer illness. Table 4.2 provides a summary of the frequencies and percentages of patient demographic variables.

Table 4.2
Patient Demographic Variables

Variable	Frequency	Percentage
Reason for Admission		
Treatment	6	12.2
Cure	1	2.0
Pain Control	6	12.2
Symptom Control	15	30.6
Other	19	38.8
Length of Illness		
Less than Six Months	10	20.4
Six to Twelve Months	10	20.4
More than One Year	29	59.2
Previous Hospitalizations		
Yes	40	81.6
No	9	18.4
Number of Previous Hospitalizations		
One to Five	27	55.1
Six to Ten	10	20.4
More than Ten	3	6.1

Supportive Nursing Actions Variable

Family perception of supportive nursing actions was measured as the total score on the Supportive Nursing Actions Questionnaire (SNA). The lower the total score the more the individual perceived that the nursing actions were supportive. A reliability analysis of the SNA Instrument revealed a high degree of internal consistency in how the participants responded to questionnaire items. A Cronbach's alpha value of 0.932 was obtained.

Scores on the Supportive Nursing Action instrument ranged from 34 to 95, out of a possible total of 140. The mean was 63.16 ($SD=15.05$), and the median was 63. Nursing actions that were identified as most helpful were: let my family member and me have time to be alone, make family member comfortable and let family help with patient care. Nursing actions perceived as least helpful included: tell me family member's suffering is over, encourage me to cry, and cry with me. The participant's responses in order of priority from most to least helpful nursing actions are outlined in Table 4.3.

The last item on the SNA requested participants to identify additional nursing actions they found helpful or not helpful which were not included on the questionnaire. (see Appendix G for summary of additional nursing actions). Sixteen participants identified additional nursing actions.

Table 4.3**Family Perception of Supportive Nursing Actions (SNA)**

Nursing Action: From Most to Least Helpful

Most or Very Helpful

1. Let my family member and me have time to be alone.
2. Try to make my family member comfortable.
3. Let me help with the physical care of my family member.
4. Give the pain medication as often as possible.
5. Show interest in answering my questions.
6. Be honest with me.
7. Do not abandon my family member.
8. Let me have time to be alone.
9. Explain treatments and procedures to my family member.
10. Answer my family member's questions honestly.
11. Keep my family member clean.
12. Give me a clear explanation of what is being done for my family member.

Helpful

13. Keep my family member's room quiet.
14. Let my family member do as much himself/herself as possible.
15. Calm my family member when he/she becomes upset.
16. Provide those things that are familiar or of value to my family member.
17. Give my family member hope.
18. Keep me informed of my family member's condition.

Somewhat Helpful

19. Stay with my family member during difficult times.
20. Help me face the reality of my family member's illness.
21. Tell me about support groups.

Not Helpful

22. Give me hope.
23. Talk to my family member about his/her fears.
24. Let me talk about my feelings.

Least Helpful

25. Hold my hand.
 26. Cry with me.
 27. Encourage me to cry.
 28. Tell me that my family member's suffering will be over.
-

Four out of 16 family members stated that meeting the patients physical needs, such as pain control and comfort, was the most helpful nursing action. Several family members qualified their statements by indicating that nurses should provide nursing care in a caring and friendly manner. Two family members identified that meeting the patients emotional needs was helpful and explained that spending time with patients was a means of meeting their emotional needs. When identifying needs which were not met, the family stated that nurses did not have enough time to spend with the patient and the family. One family member rationalized the nurses apparent lack of time by pointing out the recent government cutbacks in medical spending. Other family members identified discrepancies in how nursing staff intervened with the patient and family. The inconsistency in care delivery was interpreted as a lack of caring, adversely influencing how helpful actions were perceived. When specifically looking at their own personal needs, family members stated that honesty and openness by the nursing staff, in how their questions were answered, was most helpful. It was apparent from the comments that several family members identified themselves as primary caregivers and did not see the need for assistance from the nurses.

The most common nursing action participants added to the list was that nurses should have a caring and friendly approach to both the patient and the family. Family members repeatedly stated that being reassured the patient was adequately cared for took priority over having any of their own needs met. These findings are consistent with findings from previous research that have indicated the most important need families identified was assurance that the patient was comfortable and well cared for (Hull, 1989). In support of findings from other studies, this study revealed that being kept informed about the patients treatments and condition was extremely important to the family (Bouman, 1884; Kristjanson, 1989a).

Family Satisfaction With Care Variable

Family Satisfaction with Care (FAMCARE) was adapted for use in this study to measure the family members satisfaction with nursing care. The scores on FAMCARE could range from 17 to 85 with lower scores indicating higher levels of satisfaction with nursing care. A reliability analysis revealed a Cronbach's alpha coefficient of 0.934, indicating a high degree of internal consistency in how the participants responded to the items on the instrument.

FAMCARE scores ranged from 18 to 50 in this study. The mean for the total population of participants was 33.19 with a SD=9.87. Generally the largest percentage of family

members were mostly satisfied with the patients pain relief, the nurses approach with the family in making them feel comfortable when visiting and the availability of the nurse to the patient. Items families were less satisfied with included family conferences, being included in decisions regarding the care of their family member and information given to the family about managing the patient's pain. Table 4.4 includes a summary of the responses to the FAMCARE Instrument.

Table 4.4

Responses to Questions on the FAMCARE Instrument

From Most to Least Satisfied

Very Satisfied

1. Pain relief
2. How comfortable nurses make you feel

Satisfied

3. Time required to get help
4. Information regarding treatments
5. Information regarding medicine received
6. Comfortable room
7. Availability of nurse to patient
8. Answers nurses give
9. Availability of the nurse to the family
10. Thoroughness of nursing assessments
11. Attention nurses pay to your needs
12. Nurses attention to patient complaints
13. Way nurses do procedures
14. Coordination of nursing care
15. Information regarding patient's pain
16. Being included in decisions regarding patient care

Undecided

17. The family conferences nurses hold
-

Family Coping Strategies Variable

F-COPES is a measure designed to assess the degree to which the respondents use particular coping strategies during a family crisis event. Strategies of coping used by families were measured as the Family Crisis Oriented Personal Evaluation Scales (F-COPES) score. A Cronbach's alpha for the F-COPES scale of 0.72 indicated a moderate degree of internal consistency in how participants responded to the scale items.

The F-COPES instrument is a 30 item questionnaire, rated on a five-point Likert-type scale, with a possible cumulative score ranging from 0 to 150. In this study the scores ranged from 86 to 127 with a mean of 108.70 and a SD of 9.35. The mean for the population in this study is higher than the reported norms (mean=94.38, SD=13.62) (McCubbin and Thompson, 1991). In addition to an overall score, five subscale values can also be obtained from the F-COPES instrument. The subscales, range of scores, means, and standard deviations are listed in Table 4.5.

Table 4.5**F-COPES Subscale Ranges, Means and Standard Deviations**

F-COPES Subscale	<u>N</u>	Range	Mean	<u>SD</u>
Acquiring Social Support (10 Items)	48	30-48	37.6	4.12
Reframing (8 Items)	45	22-40	30.6	4.16
Seeking Spiritual Support (4 Items)	48	4-20	13.2	4.53
Mobilizing Family to Acquire and Accept Help (4 Items)	48	7-20	15.06	2.76
Passive Appraisal (4 Items)	48	8-20	13.7	2.72

Hypotheses Testing

The hypothesis tested in this study was: There is a statistically significant relationship between the variables of family perception of nursing support and family satisfaction with care, and the variable of family coping.

Hypothesis One

There will be a statistically significant relationship between family perception of nursing support and family coping.

Family perception of nursing support was measured as the cumulative sum of scores on the SNA. Family coping was measured as the sum of scores on the F-COPES. A multiple regression analysis was carried out between total scores on the SNA and F-COPES, as well as between SNA scores and

scores on each of the five sub scales of F-COPES. The results of the statistical analysis between total scores on the SNA and F-COPES instruments revealed that there was no significant relationship between the nursing support that family members of terminally ill patients perceive and family coping ($r=.21$; $F=1.45$; $df=5,28$; $p\geq.24$). The F-COPES instrument was broken down into five subscales and a multiple regression was done to determine the relationship between family perception of nursing support and use of coping strategies. Table 4.6 outlines the specific results from the multiple regression analysis.

Table 4.6

Multiple Regression Between Total SNA and F-COPES Subscales

Variable	Beta	T	Sig T
Passive Appraisal	.03	0.14	.89
Spiritual Support	-.03	-0.18	.86
Social Support	-.33	-1.80	.08*
Reframe	.38	1.96	.06*
Mobilization	.12	0.57	.57

* $p>0.05$

Results from the multiple regression revealed that the contribution of F-COPES subscales of acquiring social support ($p=0.08$) and reframing ($p=0.06$) to the prediction of

SNA approached significance. The directional trend was very interesting and supported results obtained when alternate statistical methods were used to analyze data from this study. It is possible that given a larger sample the likelihood of significance may have been greater.

Hypothesis Two

There will be a statistically significant relationship between family satisfaction with care and family coping strategies.

A multiple regression analysis was used to test this hypothesis. Family satisfaction with care was measured as the total score on the FAMCARE Instrument. The lower the score the greater the level of family satisfaction with nursing care. Multiple regression analysis was done using total scores for the FAMCARE with total scores for the F-COPES, as well as for the total FAMCARE with total F-COPES subscale scores. The analysis revealed that there was no significance for any combination of the measures therefore the null hypothesis was accepted indicating that there was no significant relationship between scores on the FAMCARE and F-COPES Instruments ($r=.22$; $F=1.90$; $df=1,36$; $p\geq.18$). Given a larger sample perhaps a significant relationship might have been found.

Hypothesis Three

There will be a statistically significant relationship between family perception of nursing support, family satisfaction with care and family coping.

Data analysis and interpretation become unwieldy when a large number of variables are measured in a single research project (Borg & Gall, 1983). Reducing variables to a few factors facilitates data analysis, especially if the number of subjects in the study are limited. McCubbin and Thompson (1991) performed an analysis on the F-COPES Instrument which revealed five subscales: acquiring social support, reframing, seeking spiritual support, mobilizing family to acquire and accept help, and passive appraisal. In this study a Principal Components factor analysis and Varimax rotation supported the five subscales found by McCubbin and Thompson. The five individual factors' alpha reliabilites as reported by the authors of the instrument and reliabilities for this study are reported in Table 4.7 on page 64.

Factor analysis on the SNA initially revealed six factors. Variables that loaded higher than 0.40 were used for the analysis. Items that were loaded on more than one factor did not contribute to the interpretation of the factors and were removed. Variables 6, 14 and 21 were removed because they each loaded high on two factors. A second factor analysis generated four factors. Variables

which loaded higher than 0.40 on the second four factor analysis were examined for emerging themes or common concepts. Each item and their contribution to the factors were reviewed, and four subscales were developed from the emerging themes. Table 4.8 on page 64 identifies themes for each factor and corresponding item numbers. (see Appendix H for items pertaining to each factor and their factor loadings).

The four themes that emerged from the factor analysis on the SNA concur with the literature on nursing support. Families identified that when they are kept informed about the condition of their loved ones and the care they receive, it conveys a message of caring and support on the part of the nurses (factor 1). Support, comfort and ease of suffering were also identified as important needs by significant others (factor 2). Nurses who are empathetic and attempt to convey their empathy in both their words, and more importantly their actions, have been perceived by families as supportive (factor 3). Finally, when families are experiencing a crisis they need time to deal with the associated emotions in an environment that allows them some privacy (factor 4). The concept of nursing support is sufficiently described by the combination of themes that emerged from the factor analysis.

A reliability analysis was computed for the four

subscales, as well as the total scale. Cronbach's alpha coefficients for the subscales were: verbal and nonverbal communication, 0.84, comfort measures, 0.83, empathy, 0.88, and respecting individual privacy, 0.71. The values for the subscales indicate a moderate to high degree of internal consistency in the manner with which participants responded to the scale items.

A factor analysis on the FAMCARE initially revealed three factors. Variables with factor loadings 0.40 or greater were used for the analysis. Variables which loaded on more than one factor were eliminated from the analysis. It was noted that one factor had only two variables which loaded above 0.40 so a second factor analysis was done and two factors emerged. The two factors were analyzed for emerging themes or concepts. Table 4.9 on page 64 describes the emerging themes and questionnaire items associated with FAMCARE factors. (see Appendix I for items that correspond with each factor and their factor loadings). The two themes that emerged from the factor analysis support the construct of satisfaction as it pertains to families of hospitalized patients. When family members are kept informed about the status of their loved one and care received, it increases their understanding so that they can feel more comfortable participating in the caregiver role. Having access to information about the patient enables that family to have

some control at a time when they can feel powerless (Factor 1). Another important component of satisfaction for the family is feeling that their loved one is cared for both physically and emotionally. In conjunction with being assured that their loved ones are adequately cared for, when the family's emotional needs are met, members feel that they are also cared for (Factor 2).

A reliability analysis was done on the two FAMCARE subscales which emerged from the factor analysis. Cronbach alpha coefficients for the subscale factors were: sharing information, 0.93, and physical/emotional care, 0.86. Both values indicate a high degree of internal consistency in the way the participants answered the questions.

Table 4.7
Cronbach's Alpha Reliabilities for F-COPES Subscale

	Previous Study (N=1244)	This Study (N=49)
ACQSOC	.83	.70
REFRAME	.81	.74
SEEKSPRT	.81	.91
Mobiliz	.70	.68
Passappr1	.62	.55
Total Scale	.87	.72

Table 4.8
Themes and Corresponding Factors for SNA Factor Analysis

Factor #	Theme	Items
1	Communication: verbal and nonverbal communication behaviours displayed by the nurse.	1,3,4,5,10,12,13,17,18,19,20.
2	Comfort: comfort and reassuring measures directed towards the patient and the family.	2,7,8,11,15,22.
3	Empathy: empathy and open support for family.	9,25,26,27,28.
4	Privacy: respect for the patient's and family's right to privacy.	16,23,24.

Table 4.9
Themes and Corresponding Factors for FAMCARE Factor Analysis

Factor #	Theme	Item #
1	Sharing Information: Keeping the family informed regarding the status and care of patient.	2,3,4,8,9,10,11,12,13,14.
2	Physical/Emotional Care: Methods in which nurses demonstrate to the family and patient that they care.	1,5,6,7,16,17.

Family Coping, Perception of Support, and Satisfaction

A canonical correlation was performed to examine the relationship between family coping and both perception of nursing support and satisfaction with care. Canonical correlation analysis was selected because it enables assessment of the relationship between two sets of

variables, in this case family coping variables and those associated with perception of support and satisfaction, without increasing the error rate. This technique compared to other univariate analyses reduce the chance of Type 1 error. The variables entered into the canonical correlation analysis were the subscales of each of the measurement instruments used in this study. The F-COPES was divided into the following five subscales: acquiring social support (acquiring support), reframing, seeking spiritual support (spiritual support), mobilizing family to acquire and accept help (mobilizing family), and passive appraisal. The SNA scale was divided into the following 4 subscales: supportive nursing communication (supportive communication), supportive nursing comfort (comfort), supportive nursing empathy (empathy), and supportive nursing privacy (privacy). The FAMCARE scale was divided into the following two subscales: family communication and information sharing (communication), and family physical and emotional care (physical/emotional care). Canonical correlations were computed to test the overall association among the five subscales of F-COPES: acquiring support; reframing; spiritual support; mobilizing family and passive appraisal, and subscales of SNA and FAMCARE: supportive communication; comfort; empathy and privacy; communication and physical/emotional care.

Results of the canonical correlational analysis between F-COPES subscales as one set, and subscales of SNA and FAMCARE as a second set, revealed one significant weighting system between the five F-COPES, six SNA and FAMCARE variables. Table 4.10 reveals that weights for reframing (0.59) and seeking spiritual support (0.50), family coping variables, are closely associated with regression weights for (SNA) supportive nursing communication (-0.60) and (FAMCARE) family physical/emotional care (-0.57). Therefore the greatest amount of variance in F-COPES subscales spiritual support, and reframing is due to scores on SNA subscale supportive communication and FAMCARE subscale physical/emotional care. A canonical analysis, giving the maximum correlation possible given this particular set of data, yielded a canonical correlation of 0.66. This correlation indicates a substantial relationship between the linear composites of the variables described above. In other words as family members' scores on the supportive communication and physical/emotional care subscales decreased, scores on spiritual support and reframing subscales increased. Since low scores on the supportive communication and physical/emotional care indicate higher perception of support and satisfaction, the results would indicate that when family perceive support in the area of communication and are satisfied with the patients physical

and emotional care they tend to use more coping strategies related to seeking spiritual support and reframing.

Further interpretation of the relationship between combined subsets of F-COPES and combined subsets of FAMCARE and SNA include visual analysis of the commonalities between each of the subsets. When examining common characteristics of the two F-COPES subsets reframing and spiritual support, items in both subsets refer to the individuals perception of the source of control in dealing with stressors. Reframing identifies a perception that the power to deal with stressors lies within the individual's own personal resources. Individuals who use reframing tend to feel the only means of handling stress is to do it themselves. Individuals using spiritual support coping mechanisms look outward to their religious beliefs and spiritual supports for assistance in coping, therefore believing the only means of coping with stressors is to look outside their own personal strengths.

FAMCARE subset physical/emotional care, and SNA subset supportive communication have visual communication as a common underlying theme. Both subsets have items that deal with nursing actions communicating visually to the family that the nurse cares. Results of the canonical correlation reveal that combined effects of visual nursing actions that communicate caring have an influence on the family member's

perception of belief in either internal or external sources of coping. Further analysis indicating the direction of the relationship is needed to describe the relationship of the variables in greater detail.

The relationship between family coping and need satisfaction was further clarified and supported by zero-order correlations among these variables. (see Appendix J for correlation matrix of all subscales). As indicated, F-COPES subscale instrument scores on reframing and seeking spiritual support correlated with SNA subscale scores on supportive communication ($r=0.63$), and FAMCARE subscale scores on physical/emotional care ($r=0.59$). A chi square analysis for significance revealed a $p=.004$ when all the canonical correlations were used. After dropping the largest canonical correlation, supportive communication, the probability increased substantially. Therefore it can be concluded that the largest canonical correlation is the only significant correlation.

The pattern of correlations in this study is consistent with the hypothesis that families who have higher levels of satisfaction with the physical and emotional care that nurses give as well as perceive that they are kept informed of what is happening to their loved one while in hospital, use more coping strategies that enable them to seek spiritual support and redefine their situation more

Table 4.10

Canonical Correlation for F-COPES, SNA and FAMCARE Scores

Variable	Weights	Correlation Between Canonical Composite and Original Variables
SET A VARIABLES		
F-COPES		
1. Aquiring Support	0.44	0.37
2. Reframing	0.59	-0.60
3. Spiritual Support	0.50	0.64
4. Mobilizing Family	-0.32	-0.30
5. Passive Appraisal	0.32	0.37
SET B VARIABLES		
FAMCARE		
6. Supportive Communication	0.14	-0.16
7. Physical\ Emotional Care	-0.57	-0.59
SNA		
8. Supportive Communication	-0.60	-0.63
9. Comfort	0.40	-0.30
10. Empathy	-0.16	-0.42
11. Privacy	-0.34	-0.41
CANONICAL CORRELATION		0.66*
SQUARED CANONICAL CORRELATION		0.44
* $p \leq .01$ N=49		

positively. Although only the relationship between family coping and supportive nursing communication was significant perhaps given a larger sample size the magnitude of the relationships of family satisfaction with emotional and physical care and coping may be recognized.

Analysis of Other Variables Associated With Nursing Support, Satisfaction With Care and Family Coping

Variables measured with the Biographical Inventory were analyzed using analysis of variance when more than two groups were formed, and a t-test was used to analyze dichotomous variables such as sex, and hospital unit. An analysis of variance was done to assess whether the following variables: relationship to patient, reason for admission, length of illness, number of previous hospitalizations, ethnic background, marital status, religious practice, and occupation could account for any differences in the mean scores of family coping, perception of nursing support, and satisfaction with care. A significance level of $p \leq 0.05$ was established for determining an acceptable difference between the means.

As indicated in Table 4.11, significant differences were found among mean total SNA scores and the occupation of family members ($p < .05$). Family members who were employed as professionals had significantly higher overall SNA means. Individuals who were employed in health professions had the

lowest means, with trade workers scoring slightly higher. The results suggest that family members who have professional occupations perceive less nursing support than family employed in nonprofessional occupations, excluding those individuals employed as health professionals. Given a sample of three in this group it is difficult to draw on any conclusions. Reasonable speculations can be made regarding the perception of nursing support from professionals. Family members in demanding professions may have less time to spend in assisting with patient care, resulting in a greater dependency on the nursing staff to support more of the patient and family's needs. Given their limited time, being kept informed and current on the patient's status and treatments becomes crucial to the family members involvement. In contrast a family member who spends more time with their loved one while hospitalized will tend to be more involved with day to day aspects of care and more accessible for interacting with the nurses.

Table 4.11

Analysis of Variance for Mean SNA Scores by Occupation Group

Source	Sum of Sq	DF	Mean Sq	F	Prob
Explained	3621.91	6	603.65	3.39	0.01
Residual	5515.80	31	177.93		
Total	9137.71	37	246.97		

Cell Means for SNA Scores by Occupational Groups

Occupation	Mean	Standard Deviation	Number of Subjects
Professional	90	9.06	4
Health Professional	51.3	11.09	3
White Collar	72	15.72	2
Blue Collar	60.9	5.20	10
Self Employed	74.5	15.72	2
Unemployed	62.9	4.24	15
Student	71	15.72	2

Family members, employed as health professionals, may have a more realistic concept of what constitutes supportive health care behaviours, influencing what they expect from nurses. Alternatively, the health professionals view of support could be affected by familiarity with hospitals and the health care system, enabling them to feel more comfortable asking questions and participating in making decisions which influence the patient.

There were significant differences among mean family coping scores for family members with different marital status and religious beliefs. Results of an ANOVA on F-COPES scores with marital status as indicated in Table 4.12, revealed that individuals who were single had the lowest mean family coping scores. ($p=0.04$). These findings are supported by previous studies which revealed that individuals who are in more permanent relationships have

access to more resources that assist them to cope during a crisis event. Previous studies have suggested that spouse support has a protective role in averting illness by facilitating coping during stressful events (Levav, I., Friedlander, Y, Kark, J. & Peritz, E., 1988). As indicated in Table 4.13, F-COPES mean scores differed depending on the individual's religious belief ($p=.005$). These findings suggest that family members who are practising Roman Catholics tend to use more variety of coping strategies.

Table 4.12

Analysis of Variance for Mean F-COPES Scores by Marital Status Groups

Source	Sum of Sq	DF	Mean Sq	F	Prob
Explained	840.18	4	210.05	2.80	0.04
Residual	2920.98	39	74.90		
Total	3761.16	43	87.47		

Cell Means of F-COPES Scores by Marital Status Groups

Marital Status	Mean	Standard Deviation	Number of Subjects
Married	107.4	1.73	31
Divorced	118	5.39	4
Separated	124	9.33	1
Single	105.3	3.87	7
Common law	120	9.33	1

Table 4.13**Analysis of Variance for Mean F-COPES Scores by Religious Practice Groups**

Source	Sum of Sq	DF	Mean Sq	F	Prob
Explained	1032.12	3	344.04	5.04	0.005
Residual	2729.04	40	68.23		
Total	3761.16	43	87.47		

Cell Means for F-COPES Scores by Religious Practice Groups

Religious Practice	Mean	Standard Deviation	Number of Subjects
Catholic	114.9	2.65	13
Protestant	107.8	2.45	16
Other	111	5.40	4
None	101.9	3.00	11

Family members who reported having some form of spiritual belief had higher overall means on the F-COPES than family who did not have any spiritual beliefs. Perhaps this can be explained by the fact that spiritual support, as a subscale of the F-COPES instrument, suggests that spiritual belief is an important component of coping. According to the Resiliency Model of Family Stress, Adjustment and Adaptation, personal resources such as religious beliefs, and community resources such as churches, provide families with emotional, esteem and network support that enables them

to cope more effectively with stressors (McCubbin & Thompson, 1991).

With family coping as the dependent variable, the combined effects of religious practice, marital status, ethnic background, employment and occupation were examined using a stepwise multiple regression analysis. Religious belief was found to be the only significant predictor of coping ($F=7.20$, $p=0.01$, $R=0.39$). Therefore, the findings on the multiple regression support the ANOVA indicating that religious belief does play a role in coping and perhaps should be given closer attention when assessing the family. It is interesting to note that marital status did not approach significance in the regression analysis. (see Appendix K for Regression Analysis). The variation can be due to the method of sampling, which was nonrandom, or the small sample size.

A series of stepwise multiple regression analysis were done with the subscales of each of the measurement instruments used in this study and the biographical variables. With acquiring social support as the family coping dependent variable, the combined effects of reason for admission, length of illness, number of previous hospitalizations, ethnic background, marital status, religious practice and employment were examined. Ethnic background was a significant predictor of acquiring social

support as a coping mechanism ($F=6.15$, $p=0.02$, $R=0.35$). Participants who were Canadian had higher coping scores in the area of acquiring social support.

When the factor of seeking spiritual support was regressed with all of the biographical variables, religious practice surfaced as the only significant predictor ($F=13.09$, $p=0.00$, $R=0.48$). This stands to reason since questions from the spiritual support subscale of F-COPES deal with religious practices and beliefs as a method of coping. Employment approached significance in the regression equation and perhaps, given a larger sample size, could have also been recognized as a predictor of coping.

With mobilization of resources as a dependent variable, the combined effects of all the biographical variables were examined in a stepwise regression analysis. Religious practice was found to be a significant predictor of mobilizing resources as a coping strategy ($F=6.73$, $p=0.01$, $R=0.37$). Employment approached significance ($p=0.06$) with this particular combination of variables.

Supportive nursing communication, a subscale of SNA, was the dependent variable in a stepwise regression analysis with all the biographical variables. Occupation surfaced as the primary predictor of supportive nursing communication ($F=6.04$, $p=0.02$, $R=0.36$), and length of illness was a second significant predictor ($F=5.48$, $p=0.01$, $R=0.46$). This

supports previous findings which have indicated that family members who were employed as professionals perceived less support. Family members had higher scores on the supportive nursing communication subscale, indicating they perceived less nursing support, when they were in professional occupations and the patient had been ill for a longer period of time.

When supportive nursing privacy was used as the dependent variable in a stepwise regression analysis with all biographical variables, a number of significant predictors surfaced. The strongest predictor of perceived nursing support in the area of respecting privacy was marital status ($F=4.76$, $p=0.03$, $R=0.32$). The second, third, and fourth significant predictors respectively were: reason for admission ($F=5.15$, $p=0.01$, $R=0.45$), employment ($F=5.67$, $p=0.00$, $R=0.55$), and religious practice ($F=5.93$, $p=0.00$, $R=0.61$). These results suggest that family members who are married tend to have lower scores on the supportive nursing privacy subscale indicating that they perceive more nursing support when privacy is assured for the patient and themselves. Also, family members who identified that their significant other was hospitalized because of cancer had lower scores, indicating that they felt more nursing support. Family who were employed also perceived more support in this area than those who were homemakers or

retired. Finally individuals who had some religious belief, in particular those aspiring to the Catholic faith, also perceived more nursing support.

Dichotomous variables such as nursing unit and sex were analyzed using a t-test. There were no significant differences in mean scores on the Supportive Nursing Actions, Family Satisfaction with Care, and Family Coping instruments between the two units or between males and females in the study. The male participants in this study did have significantly higher means on the passive appraisal subscale of the F-COPES instrument reporting using more of the ineffective coping mechanisms listed in the instrument ($t=-2.5$, $p=0.02$). This finding corresponds with subscale norms for males published by McCubbin, Olson, and Larsen (1981) indicating that males consistently reported using more passive appraisal coping strategies.

Summary of Results

The following is a summary of the findings in this study.

1. A significant relationship was not found between total scores on the Supportive Nursing Action (SNA) and Family Coping (F-COPES) instruments.
2. The SNA instrument scores were regressed on five F-COPES subscale scores, resulting in a significant

correlation between SNA scores with acquiring support and reframing scores.

3. The SNA scale was interpreted using a factor analysis of four factors and 25 variables.
4. The FAMCARE scale was interpreted using a factor analysis of two factors and 16 variables.
5. Using five F-COPES subscales as dependent variables a canonical correlation analysis was done with four SNA and two FAMCARE subscales as independent variables. Strong correlations were found between combinations of F-COPES subscales, spiritual support and reframing with SNA subscale supportive communication and FAMCARE subscale, physical/emotional care. The only significant relationship was between spiritual support and reframing with supportive communication, accounting for 73% of the variance in seeking support and reframing coping mechanisms.
6. There were significant differences in mean scores in SNA and occupation. Family employed as professionals had higher overall SNA means indicating lower perception of nursing support.
7. There were significant differences among mean scores of different marital status groups on family coping. Single family members had lower overall F-COPES means

indicating lower coping scores.

8. There were significant differences in mean scores of family coping and religious practice. Family members who were Roman Catholics had highest overall coping means indicating higher levels of coping.
9. Religious practice was the only biographical variable on a stepwise multiple regression analysis that significantly accounted for most of the variance in family coping. Perception of nursing support and family satisfaction with care were not significantly explained by the participants' response to reason for patient admission, length of illness, relationship to the patient, marital status, ethnic background, religious practice, employment, and occupation.
10. Regression of each subscale of F-COPES, SNA and FAMCARE was calculated on all the biographical variables. Ethnic background was significantly correlated with acquiring support and responsible for most of the variance in acquiring support scores. Similarly, religious practice was significantly correlated with spiritual support, accounting for most of the variance in seeking spiritual support family coping scores. In calculating the regression of mobilizing family subscale scores on the biographical variables, a significant relationship was found with religious

practice, which accounted for most of the variance in mobilization of family resources coping scores. When supportive communication was regressed with the biographical variables, significant correlations were found between supportive communication, occupation and length of illness. In a stepwise regression analysis, occupation was the strongest predictor of supportive communication and length of illness was second. A similar stepwise regression analysis revealed a significant relationship between privacy and a number of biographical variables. The following were found to be significant predictors of perception of nursing support in the area of privacy starting with the variable responsible for the most variance of privacy subscale scores:

- 1) marital status
- 2) reason for admission
- 3) employment
- 4) religious practice.

11. A t-test between sex and scores on each of the instrument subscales revealed a significant difference in the mean scores of males and females on the passive appraisal subscale. There were no significant differences in means between males and females on any of the other subscales. There were no significant

differences found in means on any of the instruments between participants from either of the two units where data was collected.

Discussion

This study was undertaken to gain more knowledge about family coping in relation to perception of nursing support and satisfaction with care during the terminal illness of a family member. When obtaining data from participants, it was the investigator's experience that family members were eager to share their perceptions of their needs. It was not unusual for family members to verbally express their thoughts and feelings to the investigator, indicating a sense of relief that someone was interested in how they felt. In several instances family members who had heard about the study approached the investigator requesting to participate. It is remarkable to note that only two family members, out of a total of 51 approached declined to participate. This would suggest that there is a need in this population for some attention even in the simple form of communication. While the results of this study provide some insights into family coping there are still many unanswered questions.

Hypothesis one

Hypothesis one stated that there would be a significant relationship between perception of nursing support and family coping during the terminal illness of a family member.

The relationship between Supportive Nursing Actions (SNA) instrument scores and Family Coping (F-COPES) scores was positive but not significant, therefore the hypothesis was not supported. The SNA score comprised the percentage of nursing actions family members identified as supportive. Most of the family members in this study perceived the majority of nursing actions as either most or very helpful. Perhaps eliminating family members described by the Head Nurses as inappropriate because they were having difficulty coping or experiencing conflicts, influenced the high means on the SNA Instrument. This finding, although, is not unlike others reported in related research studies. Prouse (1984) identified that the majority of family members in his study had reported their needs as being met. This was supported by Reider (1989) who found that nine out of ten most important needs were met for ninety percent of families of critically ill patients in intensive care units. Several factors could have contributed to the nonsignificant findings. A consequence of having a volunteer group for a study is that volunteer subjects are likely to be a biased sample of the target population. Perhaps individuals who

participated in this study perceived a high degree of support from nurses and recognized an opportunity to express their gratitude. Family members who were discontented may have avoided participating in the study as a sign of protest. Another factor which might have influenced the results is difficulty some participants expressed having when answering some of the questions on the SNA instrument. As one family member stated, "it's difficult to know if something is helpful when you have not experienced it".

Examining the results of a multiple regression analysis, between the five subscales of family coping and supportive nursing action instrument, several variables approached significance. Acquiring social support and reframing accounted for 20% of the variance in SNA scores ($p=0.08$, $p=0.06$). Since the sample size for this study was limited to 49 participants, given a larger sample, significance of the two family coping subscale variables with nursing support might have been reached. Unfortunately, there is insufficient information from the literature to support these findings since little attention has been paid to studying the effects of nursing support on family coping.

Hypothesis Two

Hypothesis two stated that there would be a significant relationship between family satisfaction with care and family coping.

The relationship between scores on the FAMCARE and the F-COPES instrument did not indicate there was a significant relationship and therefore the hypothesis was rejected. Analysis of F-COPES subscales with FAMCARE scores, as well, did not reveal any significant relationships. The unsupported hypothesis was difficult to explain since it contradicted even the very basic human needs theory, that when applied to the family would suggest higher levels of support in meeting needs influences a more optimal state of wellness (Yura & Walsh, 1988).

The same factors that influenced nonsignificant findings in the analysis of the variables in the first hypothesis could have influenced the findings in the second hypothesis. Another possible factor contributing to the non significant relationship between satisfaction and coping may be that participants responded to the satisfaction questionnaire in a guarded manner. Out of concern for the patient, respondents may have avoided expressing any discontent fearing repercussion on their loved one's care.

Hypothesis Three

Hypothesis three stated that there would be a significant relationship between family perception of nursing support, family satisfaction with care, and family coping.

Initial analysis of each measurement instrument with another revealed a high correlation between the SNA and FAMCARE instruments ($r=0.56$, $p=0.00$). There were no significant correlations between either the SNA or FAMCARE instruments with the F-COPES instrument. The three measurement instruments used in this study were divided into subscales following factor analysis. Canonical correlation analysis revealed a number of relationships between the subscales of each of the three instruments. Subscales of family coping, seeking spiritual support and reframing were positively correlated to SNA subscale supportive nursing communication, and FAMCARE subscale physical and emotional support. The only significant correlation, though, was between the F-COPES subscales and SNA communication. The value of communication especially in relation to being kept informed has been repeatedly demonstrated in many studies.

It is noted in the literature review that when families are kept informed about their loved ones progress and treatments they in turn feel their most important need has been met. Having access to information is a means of obtaining control. This becomes paramount when families are in situations where they feel little or no control. When a

family member is hospitalized with a terminal illness families report feeling powerless over what is happening with their loved ones. Wright & Dyck (1984) found that families expect nurses to explain daily procedures, tests, treatments, patient needs and possible side effects. The need for this form of communication increases as the time of death gets closer. Information was viewed as helpful in assisting families to cope more realistically and effectively with the immediate future. Derdiarian (1989) found strong support for the prediction that increased information leads to increase in satisfaction and coping.

It is interesting to note that family perception of supportive communication from nurses is correlated with family use of seeking spiritual support and reframing coping mechanisms. One can speculate that perhaps individuals who tend to rely on their religious beliefs for support and try to look at situations more positively, internalize both nurses verbal and nonverbal behaviours, as supportive. It is difficult to speculate whether individuals who use these coping mechanisms look for more ways to receive communication or if the result of the communication assists them to approach the stressful situations more positively. Further research would help to develop a better understanding of the interrelatedness of the variables.

Discussion of Related Variables

When coping was analyzed as the dependent variable with various biographical independent variables, a number of significant relationships surfaced. Both marital status and religious practice influenced family coping scores. This finding was not surprising since there is a multitude of literature identifying that individuals who are in stable marital relationships generally cope better during a crisis, than those who are unattached. It stands to reason that given a stable relationship, a partner can be a source of support by virtue of just being available to talk with.

The influence that religious practice has on coping can be easily explained in that one of the subscales of the family coping instrument deals solely with seeking spiritual support. Religious practice was also found to be a significant predictor of mobilization of resources and respect for privacy. The coping literature clearly identifies the important role that religious beliefs can have on an individual's ability to cope. Religion was identified as the most important factor that assisted families in tolerating the chronic condition of husband/father absence during prolonged separation (McCubbin, et al., 1976). Families reported the ability to make sense of their child's cystic fibrosis by in part using a religious philosophy way of life (Venters, 1981).

A significant relationship was found between perception of nursing support and occupation. The results indicated that family members who were in professional occupations perceived the least amount of nursing support and family members employed in a health related capacity perceived the most amount of support. A possible explanation for these results is that individuals who are employed as professionals may have a higher expectation than non professionals of what nurses do to support the patient and the family. Professionals, given higher incomes, may have access to more resources. This in turn may influence their expectations of resources which should be available for the patient. As well, associated with perhaps more demanding jobs and time commitment, the professional may have less time to spend visiting their loved ones. Limited time can increase the families' expectations of what should be done for their family when they are not there. The professional, as well, may not be as available to participate in ongoing communication with the nurses. In contrast, family members employed in the health field may have a more realistic perception of the boundaries of nursing support, meeting more of their expectations.

Length of illness was also found to be a significant predictor of nursing support. Apparently family members of patients who had been ill for longer periods of time

perceived less support. Perhaps nurses make basic assumptions about the needs of families in relation to how long the patient has been ill. Nurses may assume that if the patient and family have known about the illness for a longer time period then they must have a good understanding of the treatments and have accepted the illness. The result is that the nurse may spend less time explaining activities and giving direction to the patient and family.

A significant relationship was found between acquiring social support and the family member's ethnic background. Individuals born and raised in Canada had higher social support coping means. An explanation for this finding could be that the sample size was unproportionately larger in the Canadian group than non Canadian groups. Alternatively, perhaps the Canadian culture promotes more use of external social supports than do other cultures. For example when compared to the Asian culture, Canadians are more willing to look outside the family for help during a crisis.

Marital status, reason for admission and employment surfaced as significant predictors of nursing support with respect to privacy. Family members who were married, employed and identified that the patient was admitted because of their cancer diagnosis perceived more support when nurses respected their need for privacy. The supportive nursing subscale respect for privacy considers

what the nurse does to ensure that the patient and family have time alone in a quiet environment. Perhaps family members who have an understanding of the nature of the patient's illness, are receiving support from a spouse and have limited time to spend with the patient, may need more private time with their loved one.

The scoring procedure for the items measuring passive appraisal on the F-COPES is inverted, resulting in an interpretation that the less the family uses passive appraisal the better it is in terms of family coping. Males had significantly higher means on passive appraisal than females in this study. These findings support normative scores for males in other studies. Males in this study used more passive appraisal coping strategies indicating ineffective coping.

Demographic variables in this study, such as religious practice, occupation, marital status, ethnic background, and reason for admission, in some ways contribute to variations in F-COPES, SNA, and FAMCARE scores. The specific impact these variables have on coping, perception of support and satisfaction needs to be developed further through research.

Discussion of Descriptive Findings

Responses to individual items on the SNA are worth exploring further. It is interesting to note that the participants in this study overwhelmingly agreed on a number of nursing actions which they did not find helpful. Nursing actions directed towards the overt emotional support of the family were assessed as not helpful. For example, 37% of the participants identified that the nurse holding their hand was not helpful, 55% identified that it would not be helpful if the nurse cried with them, and 55% identified that if the nurse encouraged them to cry it would not be helpful. These findings were perplexing in that there was little in the literature to support them, in fact most of the literature contradicted these findings.

Since Kubler-Ross's research on the stages of loss, nurses have been instructed to support the family who is grieving by facilitating them to accept the loss and deal with the related feelings. When facilitating expression of these feelings, the nurse was advised to hold the family members hand, help them cry and cry with them. Have needs of the family changed over time or is it that the family has not been sufficiently involved in identifying their own needs, especially in the area of emotional support? Perhaps the family is changing and in its evolution may need less emotional support from nurses and more information that will

empower them to make decisions regarding their own needs as well as those of the patient. It would appear that family perceptions of support differ from those who are delivering the support. This is an area where research should be done to determine the differences in perceptions between families and nurses.

The last section of the SNA instrument asked family members to identify nursing behaviours they found to be supportive or nonsupportive that were not identified in the questionnaire. A comment that was repeated on a number of questionnaires was that the nurse was too busy and rushed. Several participants went as far as providing a rationale for the nurses apparent lack of time by explaining the impact of health care budget restraints and evaluating the nature and lack of value of some nursing functions. The important point is that family members are closely observing nursing behaviours and making assumptions about the value of nursing functions in relation to their own needs. Unfortunately, they are not communicating their concerns to the nurses. It appears that family members have needs, observe that the nurse is busy, rationalize the nurses behaviour and assume that the nurse does not have enough time to meet the patient's, let alone, their needs. This type of behaviour conjures up a perpetual cycle of events that lead to communication breakdown, dissatisfaction and

frustration. The family eventually feels unimportant, avoiding the nurse and in turn the nurse interprets the family's lack of interaction as an indication that the family is coping.

Significance of Findings on Resiliency Model

The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1991) was used to guide the development of this study. Findings from this study support the Resiliency Model since for the most part the families demonstrated varying degrees of adaptation to changes brought on by family illness. Demonstrated in how questions were answered on the measurement instruments, family members were able to identify adaptive strengths, accurate perceptions of what was needed to assist them to cope and resources which could assist them to meet their needs. Stress as a result of a terminal illness in a family member was dealt with by using various combinations of coping strategies that included inner personal resources as well as external supports.

CHAPTER FIVE

CONCLUSIONS AND RECOMMENDATIONS

Conclusions

The family of the patient with cancer shares in the cancer experience. The experience can be different from one family to the next and even from one family member to another. Confronted with ongoing uncertainties, which are precipitated by the often rocky course of cancer, can be very stressful for the family. Why is it that when confronted with the same stressor, such as terminal cancer illness, some families grow stronger and others become weaker? Studies have shown that the way in which individual's perceive the stressor, and resources available to them, can affect their ability to cope with difficult situations. Nurses can assist the family to cope by implementing strategies that are based on careful assessment of factors that influence family coping. The purpose of this study was to describe the relationships between family coping, perception of nursing support and satisfaction with care in families who are experiencing a terminal cancer illness. The participants in this study were family members of patients who were inpatients in a cancer treatment facility and had a palliative care prescription on their charts. Of the 49 participants, 33 were females, 16 were males and the majority were either the spouse or children of

the patient. The majority of participants in the study had scored above the normal ranges for family coping, and had scores on both the Supportive Nursing Action and Family Satisfaction with Care questionnaires that indicated high perception of support and satisfaction.

Based on the findings of this study the following conclusions were reached with this sample:

1. Factor analysis of the SNA instrument revealed 4 concepts that were interpretable, with high alpha reliability coefficients. Factor analysis of the FAMCARE instrument revealed two concepts that were interpretable, with high alpha coefficients.
2. The use of family coping strategies acquiring social support and reframing are related to perception of nursing support.
3. The use of family coping strategies seeking spiritual support and reframing are significantly correlated to perception of nursing support related to the nurses communication behaviours. A strong nonsignificant correlation was found between seeking spiritual support and reframing with how satisfied the family was with physical and emotional care that nurses gave.
4. Findings indicated that family coping means were explained mostly by the participant's religious practice and marital status. Individuals who were practising Roman

Catholics and individuals who were married scored higher on family coping. Of the five specific family coping subscales, acquiring social support was closely correlated with ethnic background and seeking spiritual support and mobilization of resources were closely correlated with religious practice. Participants who were Canadians had higher means on acquiring social support. Participants who reported that they were Roman Catholics had higher means on seeking spiritual support and mobilization of resources.

5. A significant relationship was noted between occupation and perception of nursing support. Participants in professional occupations had the highest means indicating lower perception of nursing support. Participants employed in health related occupations had the lowest means indicating higher levels of perception of support.

6. Of the four specific Supportive Nursing Action subscales, most of the variance in mean scores of supportive nursing communication was due to the participant's occupation and length of illness. As described previously, professionals had higher mean scores and individuals in health occupations had the lowest means. An interesting finding was that the longer the patient and family had known about the cancer illness the less the family perceived support in the area of communication from the nurses.

7. Most of the variance in SNA subscale, respect for

privacy, was attributed to marital status, reason for admission, employment and religious practice. More specifically, individuals who were married, stated that the patient was admitted because of the cancer, employed, and of Roman Catholic faith reported perceiving more support when nurses allowed them privacy with the patient.

8. Analysis of scores between males and females on each of the instruments revealed a significant difference on the passive appraisal, coping subscale. Males, in this study, had significantly higher means in this particular family coping subscale. Since the passive appraisal subscale deals with strategies that promote ineffective coping, it would appear that the male population of this sample use more ineffective strategies than females.

Limitations of the study

Published reports in which the Family Crisis Orientation Personal Evaluation Scales (F-COPES) was used provided adequate validity and reliability statistics. However, when a reliability analysis was done for this study, the alpha coefficient was moderate. The F-COPES instrument mean for this study was higher than the published norms. A plausible explanation for the high scores is that family may have responded to the questions as to how they perceived the family should act and not necessarily what the

family does to cope. Publications where the SNA was used did not report validity and reliability statistics for the instrument. Reliability analysis of the SNA instrument for this study revealed a high alpha coefficient. The scores on this instrument were high, which may have been associated with difficulty some participants had in answering some of the questions.

Some limitations related to the design of the study were sample size, sample selection, and sampling process. A sample size of 49 limits the degrees of freedom and power of the statistical tests. In several analysis where results showed small correlations that approached significance, a larger sample size could have demonstrated a stronger relationship between the variables. A convenience sample was used in this study therefore generalizations cannot be made to the larger population. The one time sampling process limited the family member's responses to their experiences at that particular moment. The participant's perception of nursing support, satisfaction and coping could have been influenced by a number of factors that occurred that day, altering the individual's perception. Although participants were assured about confidentiality and that they would not be identified, there may have been concerns that critical responses would influence the care there loved ones receive.

Implications for Nursing

The findings of this study suggest implications for nursing practice, education, research and administration. Although this study was correlational and does not establish causal relationships, it is important to note that the higher the levels of perception of nursing support and satisfaction, the more coping strategies a family uses. More specifically the family coping strategies of seeking spiritual support and reframing are influenced mostly by the communication behaviours the nurse displays towards the patient and the family. Families have identified open and honest communication as a vital need in assisting them to adjust to the stressors associated with illness of a family member. Findings from this study support previous research confirming the need for open communication between nurses and families.

Support does have an influence on how the family copes with the stressors associated with a terminal cancer illness. Analysis of comments family members made on the SNA questionnaire revealed that the family closely observes the nurses' behaviours and draws conclusions on those observations. Some family members make excuses for nurses when they appear "too busy" to offer adequate support. At the same time, families are aware of their needs and are more than willing to share their perceptions with

individuals who take the time to ask. When families remain silent, not expressing their needs, they are often judged as "coping well" and not given the attention needed. The obvious solution, and one that has been supported by the findings in this study, is ongoing open and honest communication that demonstrates caring and interest. The nurse can communicate caring and concern verbally and nonverbally. As expressed by several participants in this study, they felt cared for when nurses smiled in greeting the family, or when time was taken to tidy the patient's room. These actions were interpreted by the family as things nurses did that were not necessarily part of their job description, but were done out of caring.

Nurses can communicate caring and concern in many ways. Nurses who expand their concept of patient to include participating members of the family will automatically include the family in assessments and interventions. Recognizing the family as a vital piece to the patient care puzzle, nurses must make information available to families regarding the nature of the illness, expectations of therapy and rationale for treatment and care. Information empowers the family with knowledge that will allow them to make sense of what is happening, prepare them for the unknown and participate in caring for the patient. Lastly nurses must take the time to talk to the family, even if they appear to

be coping well, to ask them questions that help them to identify their needs, and be available to listen once the questions are asked. Clinical judgements regarding the needs of the family must not allow for invalidated assumptions but must evolve from excellent interview skills that elicit the information needed for nurses to implement interventions that assist family members to cope. The challenge in nursing is that of re-evaluating assumptions about what nurses think is best for cancer families and instead, helping families rediscover what is best for themselves (Thorne, 1985). Through nursing education that incorporates assessment of the family, not only for paediatrics but as a fundamental aspect of all nursing assessments, and continued family research, family members will be recognized as recipients of care as well as partners in patient care.

Recommendations for Study

As a result of the findings in this study, the following recommendations are made for future research:

1. Replication of the study with a larger sample size drawn from a wider range of settings.
2. Repeated studies to better develop the Supportive Nursing Action, and Satisfaction with Nursing Care instruments.

3. Replication of the study with more focus on the influence of demographic variables such as religion, culture and social status.

4. Replication of the study comparing the family members, patient and nurses perceptions of nursing support and satisfaction.

5. Intervention studies to determine the effect of supportive nursing interventions on family coping. Examples suggested from the findings in this study are: the effect nursing communication has on use of family coping strategies, the effect of nonverbal nursing actions on family coping and the effect of using a supportive nursing assessment instrument on family care satisfaction.

6. An extension of the study to determine the effect of past experience with illness, and different stages of cancer illness have on families perception of support and satisfaction.

Summary

A cancer diagnosis can create disorganization within the entire family unit. When the diagnosis becomes terminal the added stress can challenge the families' coping mechanisms. Nurses can help families to cope by assessing what the family needs and assisting them to meet their needs. The objective of this study was to assess the

relationship between perception of nursing support, satisfaction with nursing care and coping in family members of patients with terminal cancer. The settings were two inpatient units in a cancer treatment facility. Forty nine family members of patients with a palliative care prescription on their chart agreed to participated in the study. The participants were given three questionnaires which measured their perception of supportive nursing actions, satisfaction with nursing care, and use of coping strategies. Other factors which could have an influence on the variables being investigated in this study were described using a biographical inventory.

The findings in this study revealed a significant relationship between scores on the Supportive Nursing Action and Family Coping instruments. Specifically, findings revealed a high significant correlation between family coping strategies of seeking spiritual support and reframing, with supportive nursing communication. In other words, participants who perceived more support from nurses when they used helpful communication behaviours, coped more effectively by seeking spiritual support and redefining their experiences more positively. Another highly correlated, but nonsignificant, relationship was found between family satisfaction with physical and emotional nursing care, and use of seeking spiritual support and

reframing coping strategies. There were no significant correlations between any other subscales of the three measurement instruments.

Statistical analysis of biographical variables with family perception of support, satisfaction, and coping, revealed a number of significant relationships. Participants in the study who were professionals had higher means on the SNA scale, indicating lower perception of nursing support. Participants who were married and practising Roman Catholics had higher coping means, indicating higher levels of coping. More specifically, individuals who were Canadian and Roman Catholic accounted for most of the variance in scores on coping subscales acquiring social support, seeking spiritual support, and mobilization of resources. Most of the variance in SNA subscale supportive nursing communication was accounted for by participants who were professionals and had known about the patient's illness for the longest period of time. Supportive nursing respect for privacy was influenced most by participants who were married, identified that the patient was admitted for treatment of their cancer, employed, and Roman Catholic. Finally, male participants in this study were found to use more passive appraisal coping strategies than females.

The findings in this study supported that there are relationships between nursing communication actions and family coping behaviours. The relationships found in this study support previous research where the variables of family coping and satisfaction have been studied. Unfortunately there is very little written about the effect that nursing support has on family coping. Further research is necessary to describe the specific effects that nursing support has on the families' ability to cope. Furthermore, intervention research is essential in testing the effect that specific communication behaviours have on the family.

Implicit in the concept of support is effective communication. Strongly suggested in the literature on family needs, and supported by this study is that family members feel supported when nurses keep them informed. The family feels empowered when they understand what is happening to the patient. Empowerment leads to a sense of control and ability to participate in caring for a loved one who is hospitalized. The benefits are recognized by both the family member and the patient. The nurse benefits as well when the family member is able to assist with the caregiving. Therefore it is imperative that nurses consider the needs of the family, especially communication related needs.

REFERENCES

- Alberta Association of Registered Nurses. (1984). Position statement on palliative care. Edmonton, Alberta.
- Bateson, G. (1979). Mind and Nature. New York: E.P. Dutton.
- Benoliel, J.Q. (1983). Nursing research on death, dying, and terminal illness: Development, present state, and prospects. Annual Review of Nursing Research. 101-130.
- Blakke, F. & Pomietto, M. (1986). Family care when a child has late stage cancer: A research review. Oncology Nursing Forum, 13(6), 71-76.
- Bomar, P.J. (1989). Nurses and family health promotion. concepts, assessments, and interventions. Baltimore: Williams and Wilkins.
- Borg, W. & Gall, M. (1983). Educational research: An introduction (4th ed.). New York: Logman.
- Bouman, C.C. (1984). Identifying priority concerns of families of ICU patients. Dimensions of Critical Care Nursing, 3, 313-319.
- Bozett, F.W. & Gibbons, R. (1983). The nursing management of families in the critical care setting. Critical Care Update, 10(2), 22-27.
- Brandt, P. & Weinert, C. (1981). The PRQ - A social-support measure. Nursing Research, 30(5), 277-280.

- Burr, W.R. (1973). Theory construction and the sociology of the family. New York: John Wiley and Sons.
- Cassell, E.J. (1975). "Dying in a technological society." Death Inside Out. In Steinfels, P. & Veatch, R. (Eds.). New York: Harper Row.
- Cassileth, B.; Lusk, E.; Strouse, T.; Miller, D.; Brown, L.; & Cross, P. (1985). A psychological analysis of cancer patients and their next-of-kin. Cancer, 55, 72-76.
- Cohen, J. (1977). Statistical power analysis for the behavioural sciences. (Rev. ed.). New York: Academic Press.
- Cooper, E.T. (1984). A pilot study on the effects of the diagnosis of lung cancer on family relationships. Cancer Nursing, 7(4), 301-308.
- Derdiarian, A.K. (1989). Effects of information on recently diagnosed cancer patients' and spouses' satisfaction with care. Cancer Nursing, 12(5), 285-292.
- Dracup, K. & Breu, C. (1978). Using nursing research findings to meet the needs of grieving spouses. Nursing Research, 27(4), 212-216.
- Driever, M.J., & McCorkle, R. (1984). Patient concerns at 3 and 6 months diagnosis. Cancer Nursing, 7(3), 235-241.
- Dyck, S. & Wright, K. (1985). Family perceptions: The role of the nurse throughout an adult's cancer experience.

- Oncology Nursing Forum, 12(5), 53-56.
- Freihofer, P. & Felton, G. (1976). Nursing behaviours in bereavement: An exploratory study. Nursing Research, 25(5), 332-337.
- Giacquinta, B. (1977). Helping families face the crisis of cancer. American Journal of Nursing, 1585-1588.
- Gardner, K. & Wheeler, E. (1987). Patient's perceptions of support. Western Journal of Nursing Research, 9(1), 115-131.
- Gillis, C.L. (1983). The family as a unit of analysis: Strategies for the nurse researcher. Advances in Nursing Science, 5(3). 50-59.
- Gotay, C. (1984). The experience of cancer during early and advanced stages: The views of patients and their mates. Social Science, 18(7), 605-613.
- Gorer, G. (1965). Death, grief and mourning. New York: Doubleday.
- Greenley, N. (1981). Dying in the hospital and at home: Perceived needs of the terminally ill and their significant others. Unpublished master's thesis, University of Calgary, Alberta.
- Hampe, S.O. (1975). Needs of the grieving spouse in a hospital setting. Nursing Research, 24(2), 113-120.
- Hinton, J.M. (1967). Dying. Baltimore: Penguin Books.

- Holing, E.V. (1983). A descriptive study of dimensions of the dying trajectory: The primary caregiver's impressions. Unpublished Masters Thesis, University of Washington.
- Howell, D. (1986). The impact of terminal illness on the spouse. Journal of Palliative Care, 2(1), 22-30.
- Hull, M. (1989). Family needs and supportive nursing behaviours during terminal cancer: A review. Oncology Nursing Forum, 16(6), 789-792.
- Irwin, B. & Meier, J. (1973). Supportive measures for the relative of the fatally ill. In M.V. Batey (Ed.), Communicating nursing research: Collaboration and competition (pp.119-128). Colorado: Western Interstate Commission for Higher Education.
- Johnson, J.L. & Norby, P.A. (1981). We can weekend. A program for cancer families. Cancer Nursing, 4(1), 23-28.
- Keck, V.E. (1977). Nurse encounters with dying and nondying patients. Nursing Research, 26, 465-469.
- Kerr, J.C. (1978). "Dying in the hospital." The Canadian Nurse, 74, 17-18.
- Kirschling, J.M. (1986). The experience of terminal illness on adult family members. Nursing in Hospice and Terminal Care, 121-137.
- Klein, R.F., Dean, A. & Bogdonoff, M.D. (1967). The impact

- of illness upon the spouse. Journal of Chronic Diseases, 20, 241-248.
- Krant, M.J. (1974). Dying and dignity. Springfield: Charles C. Thomas.
- Kristjanson, L.J. (1986). Indicators of quality of palliative care from a family perspective. Journal of Palliative Care, 1(2), 8-17.
- Kristjanson, L.J. (1989a). Development of a scale to measure family perceptions of the quality of palliative care. Unpublished manuscript.
- Kristjanson, L.J. (1989b). Validity and reliability testing of the FAMCARE scale: A pilot test. (article under review).
- Lasagna, L. (1970). "Physicians' behaviour toward the dying patient." In Brim, O.G. (Ed.). The Dying patient. New York: Russell Sage.
- Levav, I.; Friedlander, Y.; Kark, J. & Peritz, E. (1988). An epidemiologic study of mortality among bereaved parents. The New England Journal of Medicine, 319(8), 457-461
- Lewandowski, W. & Jones, S. (1988). The family living with cancer. Nursing interventions throughout the course of living with cancer. Cancer Nursing, 11(6), 313-321.
- Lewis, F.M. (1986). The impact of cancer on the family: A critical analysis of the research literature. Patient

Education and Counselling, 269-289.

Lewis, F.M. (1983). Family level services for the cancer patient: Critical distinction, fallacies, and assessment. Cancer Nursing, 6(3), 193-200.

Litman, T.J. (1974). The family as a basic unit in health and medical care: A social behavioral overview. Social Science and Medicine, 8, 495-519.

Lovejoy, N. (1986). Family responses to cancer hospitalization. Oncology Nursing Forum, 13(2), 33-37.

Mayer, D.K. (1986). Cancer patients' and families' perceptions of nurse caring behaviours. Topics in Clinical Nursing, 8(2), 63-69.

McCubbin, H. & McCubbin, M. (1991). Family system assessment in health care. In McCubbin, H. & Thompson, A. (Eds.), Family assessment inventories for research and practice (pp. 53-80). Wisconsin: University of Wisconsin-Madison.

McCubbin, H.I. & Thompson, A. (1991). Family Assessment Inventories for Research and Practice. (2nd ed). The University of Wisconsin-Madison: Wisconsin.

McCubbin, H. & Patterson, J. (1983). Family stress and adaptation to crisis. In D.H. Olson & B.C. Miller (Eds.), Family studies review yearbook (Vol. 1, pp. 87-106). Beverly Hills: Sage Publications.

McCubbin, H.I., Olson, D. & Larsen, A. (1981). Family

- crisis oriented personal scales. In C. Davidson (Ed.), Systematic assessment of family stress, resources and coping: Tools for research, education and clinical intervention. St. Paul: University of Minnesota.
- McCubbin, H.I., Patterson, J. & Wilson, L. (1981). Family inventory of life events and changes. In C. Davidson (Ed.), Systematic assessment of family stress, resources and coping: Tools for research, education and clinical intervention. St. Paul: University of Minnesota.
- Molter, N.C. (1979). Needs of relatives of critically ill patients: A descriptive study. Heart and Lung, 8(2), 332-339.
- Montagu, A. (1970). The direction of human development. New York: Hawthorn.
- Mulhern, P. (1986). Identification of nursing interventions delivered to terminal cancer patients at home. In R. McCorkle & G. Hongladaron (Ed.). Issues and Topics in Cancer Nursing (pp. 239-250). New-York: Appleton Century Croft.
- Oberst, M. & James, R. (1985). Going home: Patient and spouse adjustment following cancer surgery. Topics in Clinical Nursing, April, 46-57.
- O'Brien, M.E. (1983). An identification of needs of family members of terminally ill patients in a hospital

- setting. Military Medicine, 148, 712-716.
- Orlando, I.J. (1961). The dynamic nurse-patient relationship. New York: G.P. Putnam's Sons.
- Parkes, C.; Benjamin, B. & Fitzgerald, R. (1969). Broken heart: A statistical study of increased mortality among widowers. British Medical Journal, 1, 740-743.
- Parkes, C.M. (1978). Home or hospital? Terminal care as seen by surviving spouses. Journal of the Royal College of General Practitioners, 28, 19-30.
- Perry, J. & Smith, M. (1985). The sign of the patient/family as a unit of care in working with terminally ill. The Hospice Journal, 1(3), 37-49.
- Pegg, P. & Metze, E. (1981). Death and dying. A quality of life. Great Britain: The Pitman Press.
- Prowse, M.D. (1984). Needs of family members of patients as perceived by family members and nurses in an intensive care unit: An exploratory study. Heart & Lung, 13, 310-311.
- Quint, J.C. (1965). Institutionalized practices of information control. Psychiatry, 28, 119-132.
- Reider, J. (1989). The Relationship of Family Needs Satisfaction and Family Coping Strategies to Family Adjustment During the Critical Illness of a Family Member. UMI Dissertation Information Service: Michigan.

- Roberts, S.L. (1986). Behavioral concepts and the critically ill patient (2nd ed.). Norwalk, Connecticut: Appleton-Century-Crofts.
- Rosenblatt, P.C. (1981). Grief in cross cultural and historical perspective. In Pegg, P. & Metze, E. (Ed.). Death and Dying. A Quality of Life. (pp.11-18). Great Britain: The Pitman Press.
- Saunders, C.M. (1967). The care of the dying. Gerontology Clinics, 9(4-6), 385-390.
- Skorupka, P. & Bohnet, N. (1982). Primary caregivers' perceptions of nursing behaviours that best meet their needs in a home care hospice setting. Cancer Nurse, 5(5), 371-374.
- Simmons, S. & Given, B. (1973). Nursing care of the terminal patient. Omega, 3, 217-225.
- Speedling, E.J. (1980). Social structure and social behavior in an intensive care unit: Patient-family perspectives. Social Work in Health Care, 6(2), 1-22.
- Statistics Canada. (1983). Cancer in Canada, Ottawa: Statistics Canada, Catalogue 82-207, table 14.
- Stember, M.L. (1977). Familial response to hospitalization of an adult family member. In M.V. Batey (Ed.), Communicating nursing research. Vol. 9: Nursing research in the bicentennial year (pp. 59-75). Boulder, Colorado: Western Interstate Commission for

Higher Education.

- Thorne, S. (1985). The family cancer experience. Cancer Nursing, 3(5), 285-291.
- Tringali, C.A. (1986). The needs of family members of cancer patients. Oncology Nursing Forum, 13(4), 65-70.
- Vachon, M.; Freedman, K.; Formo, A.; Rogers, J. & Lyall, W. (1977). The final illness in cancer: The widow's perspective. Canadian Medical Association Journal, 117, 1151-1154.
- Venters, M. (1981). Familial coping with chronic and severe childhood illness: The case of cystic fibrosis. Social Science and Medicine, 15, 289-297.
- Wegman, J.A. (1979). Avoidance behaviours of nurses as related to cancer diagnosis and/or terminality. Oncology Nursing Forum, 6(3), 8-14.
- Welch, D. (1981). Planning nursing interventions for family members of adult cancer patients. Cancer Nursing, 4, 365-370.
- Wellisch, D.k.; Jamison, K.r. & Pasnau, R.O. (1977). Psychosocial aspects of mastectomy II: The man's perspective. American Journal of Psychiatry, 135, 543-546.
- Wright, K. & Dyck, S. (1984). Expressed concerns of adult cancer patients' family members. Cancer Nursing, October, 371-374.

Wright, L. & Leahey, M. (1984). Nurses and families: A guide to family assessment and intervention.

Philadelphia: F.A. Davis Company.

Yura, H. & Walsh, M. (1988). The nursing process (5th ed.). Norwalk, Connecticut: Appleton & Lange.

APPENDIX A

BIOGRAPHICAL DATA QUESTIONNAIRE

Please answer the following questions. Your answers will be used only for the purpose of the study and will be kept confidential.

1. How old are you? _____
2. Are you MALE or FEMALE? _____
3. What is your relationship to the patient? _____
4. When was the patient admitted to this unit? _____
5. Why was the patient hospitalized? _____
6. How long has the patient had this illness? _____
7. Has the patient been hospitalized before? If so how many times? _____
8. What is your ethnic background? _____

For each of the following questions, please circle the answer that best describes your situation.

Are you SINGLE, MARRIED, SEPARATED, DIVORCED or WIDOWED?

Do you have a particular religious belief? yes no

If your answer was yes then which of the following religious beliefs do you have?

1. Protestant
2. Catholic
3. Jewish
4. Other _____

Are you presently:

1. Unemployed
2. Employed
3. Retired
4. Homemaker

If employed, please describe your occupation. _____

APPENDIX B

SUPPORTIVE NURSING ACTIONS QUESTIONNAIRE

Family members of patients have a variety of needs. Nurses can be helpful in meeting some of those needs. I have several examples of nursing actions. Please circle the number that best describes how helpful each of the following nursing actions **WOULD BE** in helping you with your needs. PLEASE circle a number for all of the questions even if you **HAVE NOT** experienced any of them.

The choices on the scale are as follows:

1	2	3	4
MOST HELPFUL	VERY HELPFUL	HELPFUL	NOT HELPFUL
5			
LEAST HELPFUL			

FOR EXAMPLE:

Help me find my way around the hospital.	1	2	3	4	5
--	---	---	---	---	---

THE NURSES:

1. Give me a clear explanation of what is being done for my family member.	1	2	3	4	5
2. Try to make my family member comfortable.	1	2	3	4	5
3. Are honest with me.	1	2	3	4	5
4. Keep my family member clean.	1	2	3	4	5
5. Keep me informed of my family member's condition.	1	2	3	4	5
6. Explain treatments and procedures to my family member.	1	2	3	4	5
7. Show interest in answering my questions.	1	2	3	4	5
8. Give the pain medication as often as possible.	1	2	3	4	5
9. Give me hope.	1	2	3	4	5
10. Do not abandon my family member.	1	2	3	4	5
11. Calm my family member when he/she becomes upset.	1	2	3	4	5
12. Provide those things that are familiar or of value to my family member.	1	2	3	4	5

1	2	3	4	
MOST HELPFUL	VERY HELPFUL	HELPFUL	NOT HELPFUL	
5				
LEAST HELPFUL				

13. Answer my family member's questions honestly.	1	2	3	4	5
14. Give my family member hope.	1	2	3	4	5
15. Stay with my family member during difficult times.	1	2	3	4	5
16. Let my family member and myself have time to be alone.	1	2	3	4	5
17. Let my family member do as much himself/herself as possible.	1	2	3	4	5
18. Help me face the reality of my family member's illness.	1	2	3	4	5
19. Talk to my family member about his/her fears.	1	2	3	4	5
20. Tell me about support groups.	1	2	3	4	5
21. Let me talk about my feelings.	1	2	3	4	5
22. Let me help with the physical care of my family member.	1	2	3	4	5
23. Keep my family member's room quiet.	1	2	3	4	5
24. Let me have time to be alone.	1	2	3	4	5
25. Hold my hand.	1	2	3	4	5
26. Cry with me.	1	2	3	4	5
27. Encourage me to cry.	1	2	3	4	5
28. Tell me that my family member's suffering will be over.	1	2	3	4	5

Please write down any additional nursing actions which you would find helpful, or have found to be helpful.

APPENDIX C

FAMILY CRISIS ORIENTED PERSONAL SCALES (F-COPES)

The Family Coping Scale is used to record how families respond to problems or difficulties. Read each of the statements and decide how well each statement describes your attitudes and behaviour in response to problems or difficulties.

The choices on the scale are as follows:

1	2	3
STRONGLY DISAGREE	MODERATELY DISAGREE	NEITHER AGREE OR DISAGREE
4	5	
MODERATELY AGREE	STRONGLY AGREE	

WHEN WE FACE PROBLEMS OR DIFFICULTIES IN OUR FAMILY, WE RESPOND BY:

1. Sharing our difficulties with relatives	1	2	3	4	5
2. Seeking encouragement and support from friend	1	2	3	4	5
3. Knowing we have the power to solve major problems	1	2	3	4	5
4. Seeking information and advice from persons in other families who have faced similar problems	1	2	3	4	5
5. Seeking advice from relatives (grandparents, etc.)	1	2	3	4	5
6. Seeking assistance from community agencies and programs designed to help families in our situation	1	2	3	4	5
7. Knowing that we have the strength within our own family to solve our problems	1	2	3	4	5
8. Receiving gifts and favours from neighbours e.g. food, mail.	1	2	3	4	5
9. Seeking information and advice from the family doctor.	1	2	3	4	5
10. Asking neighbours for favours and assistance	1	2	3	4	5
11. Facing the problems "head-on" and trying to get a solution right away	1	2	3	4	5
12. Watching television	1	2	3	4	5
13. Showing that we are strong	1	2	3	4	5

1	2	3
STRONGLY DISAGREE	MODERATELY DISAGREE	NEITHER AGREE NOR DISAGREE
4	5	
MODERATELY AGREE	STRONGLY AGREE	

14. Attending religious services	1	2	3	4	5
15. Accepting stressful events as a fact of life	1	2	3	4	5
16. Sharing concerns with close friends	1	2	3	4	5
17. Knowing luck plays a big part in how we are able to solve family problems	1	2	3	4	5
18. Exercising with friends to stay fit and reduce tension	1	2	3	4	5
19. Accepting that difficulties occur unexpectedly	1	2	3	4	5
20. Doing things with relatives (get-togethers, dinners, etc.)	1	2	3	4	5
21. Seeking professional counselling and help for family difficulties	1	2	3	4	5
22. Believing we can handle our own problems	1	2	3	4	5
23. Participating in religious activities	1	2	3	4	5
24. Defining the family problem in a more positive way so that we do not become too discouraged	1	2	3	4	5
25. Asking relatives how they feel about problems we face	1	2	3	4	5
26. Feeling that no matter what we do to prepare, we will have difficulty handling problems	1	2	3	4	5
27. Seeking advice from a minister	1	2	3	4	5
28. Believing if we wait long enough, the problem will go away	1	2	3	4	5
29. Sharing problems with neighbours	1	2	3	4	5
30. Having faith in God	1	2	3	4	5

APPENDIX D

FAMCARE SCALE

INSTRUCTIONS: Please answer the following questions about how satisfied you are with the care that you and your family member have received. Please circle the number that best matches your experience.

The choices on the scale are as follows:

1	2	3	4
VERY SATISFIED	SATISFIED	UNDECIDED	DISSATISFIED
5			
VERY DISSATISFIED			

HOW SATISFIED ARE YOU WITH:

- | | | | | | |
|---|---|---|---|---|---|
| 1. Ways nurses relieve the patient's pain. | 1 | 2 | 3 | 4 | 5 |
| 2. Information nurses give about the patient's treatments. | 1 | 2 | 3 | 4 | 5 |
| 3. Answers the nurses give you. | 1 | 2 | 3 | 4 | 5 |
| 4. Information given about the medicine the patient receives. | 1 | 2 | 3 | 4 | 5 |
| 5. The comfort of the hospital room. | 1 | 2 | 3 | 4 | 5 |
| 6. The family conferences nurses hold. | 1 | 2 | 3 | 4 | 5 |
| 7. Nurse's attention to the patient's complaints. | 1 | 2 | 3 | 4 | 5 |
| 8. The way nurses do tests and procedures. | 1 | 2 | 3 | 4 | 5 |
| 9. Availability of the nurses to the family. | 1 | 2 | 3 | 4 | 5 |
| 10. Coordination of nursing care. | 1 | 2 | 3 | 4 | 5 |
| 11. Time required to get help. | 1 | 2 | 3 | 4 | 5 |
| 12. The way you are included in decisions about the patient's nursing care. | 1 | 2 | 3 | 4 | 5 |
| 13. Information given about how to manage the patient's pain. | 1 | 2 | 3 | 4 | 5 |
| 14. How thoroughly nurses assess the patient's needs. | 1 | 2 | 3 | 4 | 5 |
| 15. How well nurses pay attention to your needs. | 1 | 2 | 3 | 4 | 5 |
| 16. How comfortable the nurses make you feel when you visit. | 1 | 2 | 3 | 4 | 5 |
| 17. Availability of the nurse to the patient. | 1 | 2 | 3 | 4 | 5 |

APPENDIX E

Family Information Letter

PARTICIPATION IN RESEARCH PROGRAMS IS ENTIRELY VOLUNTARY. VOLUNTEERS ARE ASSURED THAT THEY MAY DECLINE TO PARTICIPATE OR TO WITHDRAW FROM THE STUDY AT ANY TIME WITHOUT PREJUDICE TO THEMSELVES OR THEIR FAMILY.

Nursing Actions Family Members of Patients Find Helpful

Dear Family Member:

I am a nurse and presently taking a Master's degree in Nursing at the University of Alberta. I am doing a study about the needs of family members of patients in hospitals, and what nurses can do to help them. It is hoped that the results of this study will be useful in helping nurses to plan care that involves the family. When I refer to family, I mean anyone who is a relative of the patient by blood, marriage, common-law relationship or live-in companion.

If you agree to participate in this study, you will be asked to complete 4 forms that ask you questions about yourself and the things nurses do that are helpful to you. This should take you about 45 minutes. The information on the forms will be kept confidential and I will be the only one that will read them. You will not be asked to put your name on any of the forms.

Please mark an X beside one of the boxes on the note attached to this letter. If you would like to participate mark an X under YES and write your phone number on the space provided. If you do not wish to participate mark an X under NO and you will not be contacted. Put the note with your response in the envelope provided, seal it and leave it at the nurses desk.

I would appreciate your help very much. Thank-you for your interest.

Yours sincerely,

Filomena Nalewajek, RN,BScN (454-7852)

.....
NO I do not want to participate in this study.

YES I want to find out more about this study and would like
the researcher to contact me at _____

PARTICIPANTS INITIALS _____.

APPENDIX F

INFORMED CONSENT

Title of Research - Nursing Behaviours Family Members of Patients Find Helpful and Their Relationship to Coping.

Researcher

Filomena Nalewajek, R.N., Bscn, Master of Nursing Candidate
Faculty of Nursing, University of Alberta.
Phone: 454-7852

Advisor

Dr. Jan Kerr, Faculty of Nursing, University of Alberta.
Phone: 492-6253

Purpose of the Study

The purpose of this study is to find out the needs of the family of patients in the hospital and identify how the nurses can be most helpful to the family.

Procedure

You will be asked to complete four questionnaires. They will take you about 20 minutes to complete. One of these questionnaires asks you for information such as your age, sex, and relationship to the patient. A second questionnaire lists nursing behaviours and asks you which ones you find most helpful. The third questionnaire lists ways families cope when they are feeling stressed. You will be asked to circle the response that best describes the way you and your family cope. The last questionnaire lists different ways nurses care for patients and their families. You will be asked about how satisfied you are with the care you receive.

I will stay in the room when you fill out the questionnaires so that I can answer your questions if you have any. When you finish filling out the questionnaires you will put them in the envelope attached and give them to me.

Risks/Benefits

Taking part in this study will not help you or the patient directly. It is hoped that knowledge gained from this study will help nurses to improve care that is given to the family. Therefore, the knowledge gained from this study can help future family members of patients in hospitals. There are no risks to you or your hospitalized family member by being part of this study.

Voluntary Participation and Confidentiality

You do not have to participate in this study if you do not want to. If you decide to participate, you can withdraw at any time you like. If you want to withdraw from the study let the researcher know. Taking part in this study or dropping out of the study will not affect the care you or your family receive.

Your name will not be put on any of the questionnaires. The only way you will be identified is by a number on top of the forms. Only the researcher will know your number. The questionnaires you fill out will be kept in a locked cabinet. These questionnaires will be destroyed 5 years after the study is finished. Your name will not be in any reports or presentations about the study.

You are asked not to talk about the study with anyone in your family. You are also asked not to discuss the study with other patients or their families. This study has not been discussed with your hospitalized family member. Any information told to you in confidence by your family member who is in the hospital should not be used to answer any questions on the questionnaires.

The results of this study will be made available to you when the study is finished. The results will also be made available to other participants in the study and the nursing staff from the units.

If you have any questions you can call the researcher, Fil Nalewajek at any time.

Consent

I, _____, have read this consent and I agree to be in the study called, 'Nursing Behaviours Family Members of Patients Find Helpful and Their Relationship to Coping'. The researcher, Fil Nalewajek, has explained the study to me and given me the opportunity to ask any questions. Fil Nalewajek has answered all my questions at this time. I have been given a copy of this consent form.

signature of participant

date

signature of researcher

date

APPENDIX G

Summary of Additional Comments on SNA Questionnaire
(As Reported by Family Members)

1. I find that my sister feels that she does not want to put anybody out of their way and will not bother the nurses. I try to encourage her to ask for help no matter how insignificant.
2. It is most helpful when nurses help family members with setting up for meals when they have difficulty due to physical problems, become familiar with family members' physical problems and pain areas and avoid aggravating painful areas when handling them. It would be helpful if nursing staff could pop in and pass time of day when family member is alone. We realize that present cutbacks have put added stress on an already busy staff, but I firmly believe that actions by nurses are important to patient recovery.
3. I have not experienced the need for nurses helping me to cope by holding my hand, encouraging me to cry, and crying with me, but I'm sure that staff here will be most helpful. My mother, who was treated here for cancer before she passed away commented that she was very well treated by the staff.
4. The nursing staff have willingly answered questions, demonstrated care and thoughtfulness and have been accessible. We have been preparing for our mother's death for 3 years so some of the questions we were not able to answer, as we did not need to use the nurses in a supportive role to help us cope.
5. Many of the answers vary depending on which nurse is looking after us. Most of them are just fantastic, dedicated, caring and helpful. Some others are not quite as good. Quite often there is not enough oxygen equipment on the floor.
6. I think keeping the patient clean and comfortable are the most helpful.
7. We thought it was very good of them to bring us in a cot to spend the nights with out loved one!
8. Control of pain is most important. Try to be upbeat as possible as well.
9. Because of the fact that we spend most of the day here, there is no need for nurses to spend support time here. The room is very small. We haven't had family conferences so there is nothing to base an opinion on.

10. Soft pillows or toss cushions in the main lounge would be helpful. Staff speak too loudly around 10 pm. Good simple food like soups for family members, at a reasonable price would be helpful.
11. Nurses could spend more time with patients if they weren't burdened with such menial, trivial tasks such as changing beds, etc. Ridiculous! Patients should be allowed to familiarize themselves with the nurses as should the family. Its always rush, rush, rush!
12. I feel best when I see my family member getting the best care possible. While I would find it helpful to be able informed about support groups, I would rather the nurses tended to; my family member than myself. I have found that I feel most at ease when I know the nurse's care about my family members health and feelings. The best nurses are honest but encouraging, they are willing to hug a patient and always have a smile. All this in turn makes the patient feel good which is encouraging to family members.
13. Courteous and friendly approach by the nurses is most helpful. There are resources available outside the hospital to help with the psychological aspects therefore these are not really helpful, and they haven't occurred.
14. I found it hard to answer these questions since I stay with my family member and so take care of mostly all her needs except for medications.
15. Being honest about his condition is most helpful.
16. I stay 24 hours a day with the patient so I take care of cleansing and comforting the patient.

APPENDIX H

Supportive Nursing Action Instrument
Factor Analysis and Factor Loadings

<u>VAR</u>	<u>FACTOR</u>			
	1	2	3	4
1	0.77	0.02	0.10	-0.04
2	0.33	0.79	0.10	-0.00
3	0.60	0.55	0.05	-0.19
4	0.82	0.13	-0.00	0.27
5	0.87	0.21	0.08	-0.03
7	0.11	0.63	0.35	0.21
8	-0.04	0.75	0.00	0.10
9	0.39	0.21	0.50	0.17
10	0.65	0.31	0.18	-0.13
11	0.30	0.54	0.44	-0.23
12	0.53	0.45	0.29	0.10
13	0.62	0.54	0.09	0.00
14	0.45	0.50	0.25	0.18
15	0.52	0.66	0.08	-0.03
16	-0.02	0.23	0.30	0.65
17	0.64	0.05	0.04	0.49
18	0.66	0.24	0.41	-0.02
19	0.67	0.05	0.42	-0.18
20	0.50	0.36	0.25	-0.00
21	0.37	0.50	0.47	-0.14
22	0.11	0.52	-0.03	0.31
23	0.05	0.16	-0.26	0.76
24	-0.07	-0.08	0.19	0.89
26	0.18	0.44	0.67	0.09
27	0.08	0.11	0.89	0.06
28	0.13	-0.10	0.83	-0.01

List of Eigenvalues For SNA Factor Analysis

<u>Factor</u>	<u>Eigenvalue</u>	<u>Pct of Var</u>	<u>Cum Pct</u>
1	10.72	38.3	38.3
2	2.82	10.1	48.4
3	2.54	9.1	57.4
4	1.90	6.8	64.2

APPENDIX I

Family Satisfaction With Care Instrument
Factor Analysis With Factor LoadingsFACTORS

<u>VAR</u>	1	2
1	0.30	0.73
2	0.79	0.29
3	0.72	0.32
4	0.62	0.46
5	-0.09	0.73
6	0.26	0.56
7	0.35	0.71
8	0.68	0.30
9	0.69	0.38
10	0.69	0.39
11	0.68	0.31
12	0.83	0.17
13	0.83	-0.01
14	0.76	0.32
15	0.54	0.13
16	0.21	0.86
17	0.18	0.89

List of Eigenvalues for FAMCARE Factor Analysis

<u>Factor</u>	<u>Eigenvalue</u>	<u>Pct of Var</u>	<u>Cum Pct</u>
1	8.52	50.1	50.1
2	2.05	12.1	62.2

APPENDIX J

Correlation Matrix for All Subscale Groups

CORRELATIONS:	COPING				
	AQSOC	REFRAM	SEEKSP	MOBIL	PASSAP
AQSOC	1.00	0.20	0.13	0.18	0.20
REFRAM	0.20	1.00	-0.26	0.21	0.19
SEEKSP	0.13	-0.26	1.00	0.19	0.09
MOBIL	0.18	0.21	0.19	1.00	-0.16
PASSAP	0.20	0.19	0.09	-0.16	1.00
FCOMM	0.00	0.15	0.06	0.18	0.02
FPHSEM	-0.05	0.26	-0.18	0.32	-0.15
SNCOMM	-0.04	0.42	-0.28	0.02	-0.09
SNCOMF	-0.08	0.26	-0.02	0.08	0.04
SNEMPA	-0.24	0.24	-0.06	0.01	-0.05
SNPRIV	-0.41	0.01	-0.13	0.05	-0.08

CORRELATIONS:	FAMCARE		SUPPORTIVE NURSING ACTIONS			
	FCOMM	FPHSEM	SNCOMM	SNCOMF	SNEMPA	SNPRIV
AQSOC	0.00	-0.05	-0.04	-0.08	-0.24	-0.41
REFRAM	0.15	0.26	0.42	0.26	0.24	0.01
SEEKSP	0.06	-0.18	-0.28	-0.02	-0.06	-0.13
MOBIL	0.18	0.32	0.02	0.08	0.01	0.05
PASSAP	0.02	-0.15	-0.09	0.04	-0.05	-0.08
FCOMM	1.00	0.54	0.20	0.74	0.40	0.21
FPHSEM	0.54	1.00	0.18	0.60	0.19	0.22
SNCOMM	0.20	0.18	1.00	0.48	0.36	-0.13
SNCOMF	0.74	0.60	0.48	1.00	0.39	0.16
SNEMPA	0.40	0.19	0.36	0.39	1.00	0.17
SNPRIV	0.21	0.22	-0.13	0.16	0.17	1.00

LEGEND

AQSOC: Acquiring Social Support
 REFRAM: Reframing
 SEEKSP: Seeking Spiritual Support
 MOBIL: Mobilizing Resources
 PASSAP: Passive Appraisal
 FCOMM: FAMCARE Supportive Communication
 FPHSEM: FAMCARE Physical/Emotional Care
 SNCOMM: SNA Supportive Communication
 SNCOMF: SNA Comfort
 SNEMPA: SNA Empathy
 SNPRIV: SNA Privacy

APPENDIX K

Multiple Regression

Dependent Variable: Family Coping

Variables in Regression Equation: Ethnic Background, Religious Practice, Occupation, Employment and Marital Status.

Variable(s) Entered on Step Number 1: Religious Practice

Multiple R	0.39	R Square	0.15
Adjusted R Square	0.13	Adjusted Error	9.18

F= 7.20

Signif F= 0.01

----- Variables in the Equation -----				
Variable	B	Beta	F	Sig F
Religious Practice	-2.38	-0.39	7.20	0.01

Dependent Variable: Acquiring Social Support

Variables in Regression Equation: Reason for Admission, Length of Illness, Number of Previous Hospitalizations, Ethnic Background, Marital Status, Religious Practice, Employment and Occupation.

Variable(s) Entered on Step Number 1: Ethnic Background

Multiple R	0.35	R Square	0.13
Adjusted R Square	0.10	Adjusted Error	3.96

F= 6.15

Signif F= 0.02

----- Variables in the Equation -----				
Variable	B	Beta	F	Sig F
Ethnic Background	-0.64	-0.35	6.15	0.02

Multiple Regression

Dependent Variable: Seeking Spiritual Support

Variables in Regression Equation: As Listed Above

Variable(s) Entered on Step Number 1: Religious Practice

Multiple R	0.48	R Square	0.23
Adjusted R Square	0.22	Standard Error	4.07
F= 13.10		Signif F= 0.00	

-----Variables in the Equation-----

Variable	B	Beta	F	Signif F
Seeking Spiritual	-1.40	-0.48	13.09	0.00

Dependent Variable: Mobilization of Family

Variables in Regression Equation: As Listed Above

Variable(s) Entered on Step Number 1: Religious Practice

Multiple R	0.38	R Square	0.14
Adjusted R Square	0.12	Standard Error	0.12
F= 6.73		Signif F= 0.01	

-----Variables in the Equation-----

Variable	B	Beta	F	Signif F
Religious Practice	-0.66	-0.37	6.73	0.01

Multiple Regression

Dependent Variable: Supportive Nursing Communication

Variables in Regression Equation: As Listed Above

Variable(s) Entered on Step Number 1: Occupation

Multiple R	0.36	R Square	0.13
Adjusted R Square	0.11	Standard Error	3.09
F= 6.04		Signif F= 0.02	

Variable(s) Entered on Step Number 2: Length of Illness

Multiple R	0.46	R Square	0.21
Adjusted R Square	0.18	Standard Error	2.97
F= 5.47		Signif F= 0.01	

-----Variables in the Equation-----

Variable	B	Beta	F	Signif F
Occupation	-0.52	-0.36	6.68	0.02
Length of Illness	1.17	0.29	4.40	0.04

Dependent Variable: Supportive Nursing Privacy

Variables in Regression Equation: As Stated Above

Variable(s) Entered on Step Number 1: Marital Status

Multiple R:	0.32	R Square:	0.10
Adjusted R Square	0.08	Standard Error:	1.85
F= 4.76		Signif F= 0.03	

-----Variables in the Equation-----

Variable	B	Beta	F	Signif F
Marital Status	0.50	0.32	4.76	0.03

Multiple Regression

Variable(s) Entered on Step Number 2: Reason For Admission

Multiple R:	0.44	R Square:	0.20
Adjusted R Square	0.16	Standard Error:	1.77

F= 5.15

Signif F= 0.01

-----Variables in the Equation-----

Variable	B	Beta	F	Signif F
Marital Status	0.53	0.34	5.83	0.02
Reason for Admission	-0.47	-0.32	5.08	0.03

Variable(s) Entered on Step Number 3: Employment

Multiple R:	0.55	R Square:	0.30
Adjusted R Square	0.25	Standard Error:	1.68

F= 5.66

Signif F= 0.00

-----Variables in the Equation-----

Variable	B	Beta	F	Signif F
Marital Status	0.58	0.37	7.61	0.01
Reason for Admission	-0.47	-0.32	5.64	0.02
Employment	0.52	0.31	5.55	0.02

Variable(s) Entered on Step Number 4: Religious Practice

Multiple R:	0.61	R Square:	0.61
Adjusted R Square	0.31	Standard Error:	1.60

F= 5.93

Signif F= 0.00

-----Variables in the Equation-----

Variable	B	Beta	F	Signif F
Marital Status	0.60	0.38	9.01	0.00
Reason for Admission	-0.48	-0.32	6.30	0.02
Employment	0.57	0.35	7.31	0.01
Religious Practice	0.36	0.28	5.01	0.03